DOCUMENT RESUME

ED 366 137 EC 302 731

AUTHOR Sowers, Jo-Ann; And Others
TITLE A Comprehensive Model To Enhance the Mastery and Functional Capabilities of Students with Physical and Multiple Disabilities. Final Report.
INSTITUTION Oregon Research Inst., Eugene.
SPONS AGENCY Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE [91]
NOTE 82p.
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS *Curriculum Development; Elementary School Students; Elementary Secondary Education; *Goal Orientation; *Multiple Disabilities; Parent Education; Personal Autonomy; *Physical Disabilities; Secondary School Students; *Student Educational Objectives; *Teaching Models
IDENTIFIERS Community Based Education

ABSTRACT

This final report describes the Mastery Project, which developed, implemented, and field tested a comprehensive model to promote the mastery orientation and functional independence of students, ages 11-20, with physical and multiple disabilities. The model includes systematic procedures to: (1) facilitate assessment of students' functional capabilities in home, community, school, and friendship domains; (2) assist students to identify and select personal goals and apply problem-solving and planning strategies; (3) enable students to direct assistance provided by others; (4) promote the ability of parents to support students' independence and autonomy; and (5) create opportunities for students to participate in community-based activities and discuss disability-related issues with successful adult mentors with similar challenges. The Mastery Project was implemented in 2 school districts with 30 students and their parents. Students were provided with weekly coaching to accomplish self-assessments, goal identification, and goal achievement. Students were also introduced to mentors, and parents were provided with monthly coaching and written materials. The project has been adopted by the Portland (Oregon) public schools. (Contains 311 references.) (DB)

***********************************************************************
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
***********************************************************************

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

● Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 366 137

# A Comprehensive Model to Enhance the Mastery and Functional Capabilities of Students with Physical and Multiple Disabilities

## FINAL REPORT

Awarded to Oregon Research Institute
as PR#H086D90001 under CFDA 84.086D

Principal Investigators

Jo-Ann Sowers, Ph.D.  Laurie E. Powers, Ph.D.  Larry K. Irvin, Ph.D.

Communication regarding this manuscript should be directed to Dr. Laurie E. Powers, Hood Center for Family Support, Dartmouth-Hitchcock Medical Center, Lebanon, NH 03756.

EC302731

BEST COPY AVAILABLE

# I. ABSTRACT

Adolescents with physical and multiple disabilities are confronted with many physical, cognitive, and psycho-social barriers to their development of optimal levels of independence and mastery orientation. If students with physical and multiple disabilities are to achieve full inclusion and grow into active, self-directed adults, they must be provided with strategies and supports to promote their independence and personal mastery.

The Mastery Project developed, implemented, and field-tested a comprehensive model that school districts and independent living programs can use to promote the mastery orientation and functional independence of students, ages 11-20, with physical and multiple disabilities. The model includes systematic procedures to (a) facilitate student assessment of functional capabilities in home, community, school, and friendship domains, (b) assist students to identify and select personal goals and apply problem-solving and planning strategies to achieve those goals, (c) enable students to direct assistance provided by others, (d) promote the ability of parents to support the growing independence and autonomy of their sons and daughters, and (e) create opportunities for students to perform community-based activities and discuss disability-related issues with successful adult mentors with similar challenges.

The Mastery Project was implemented in two school districts with 30 students and their parents. Students were provided with weekly coaching to accomplish self-assessments, goal identification, and goal achievement. Students received specific in-situ coaching in the application of strategies to manage support. Students were also introduced to mentors with whom they performed community-based activities and participated in peer support conferences. Finally, parents were provided with monthly coaching and written materials to enhance their capabilities to support their son's and daughter's independence and personal feelings of mastery.

The products of the Mastery Project include a manual with guides for students, educational facilitators, parents, and independent living programs that describe strategies for implementation of each model component. The Mastery Project has been disseminated regionally and nationally. It has also been permanently adopted for use by Portland Public Schools and is currently undergoing further development and dissemination through federally-funded outreach and model demonstration activities.

# II. TABLE OF CONTENTS

I. Abstract i
II. Table of Contents ii
III. Rationale and Theoretical Foundation 1
    A. Rationale for the Mastery Project 1
    B. Conceptual Framework 5
IV. Model and Participants 14
    A. Model Components 14
    B. Participants 25
V. Goals and Objectives 26
    1. Development 26
    2. Project-Initiated Implementation and Field-Testing 27
    3. District-Initiated Implementation 28
    4. Field-Test of the Model 29
    5. Evaluation 30
    6. Model Dissemination 31
VI. Problems and Solutions 32
VII. Evaluation Strategies 35
    Case Descriptions 36
VIII. Project Impact 51
IX. Further Information and Assurances 52
X. References 53

## III. RATIONALE AND THEORETICAL FOUNDATION

### (A.) Rationale for the Mastery Project

#### Inclusion Challenges

During the last two decades, much progress has been realized in efforts to enhance the inclusion and functional competence of youth who experience severe disabilities. An impressive array of educational technologies have been developed for teaching a wide range of skills within instructional, vocational, and independent living domains (e.g., Bellamy, Horner, & Inman, 1979; Horner, Meyer, & Fredericks, 1986; Sailor & Guess, 1983; Snell, 1983; Wehman, 1981). However, the vast majority of these efforts have focused on students who experience mental retardation. Less attention has been directed to the development of strategies to enhance the well-being of students with physical and multiple disabilities, such as cerebral palsy, spina bifida, and traumatic brain injury. Due to the nature and severity of their disabilities, these students pose some unique challenges that necessitate the application of specific approaches to facilitate their functional competence, inclusion, and quality of life.

Approximately 700,OOO Americans experience cerebral palsy (Kneedler, Hallahan, & Kauffman, 1984) and 2,425,000 children under the age of 21 experience physical disabilities that substantially limit their functional engagement in life activities (Goldenson, Dunham, & Dunham, 1979). Recent national surveys indicate that only 46% of students with physical disabilities and 9% of students with multiple disabilities attend mainstreamed classes, while 46% of these students continue to attend special schools (The ICD Survey III, 1989). The range of post-educational employment, attendant care, and residential options available to persons who experience significant physical disabilities continues to be meager (McCarthy, 1986; Pietruski, Everson, Goodwyn, & Wehman, 1985). Although the Independent Living Movement has done much to enhance the independence of adults with physical disabilities, it has had relatively minimal impact on school-age students and their parents, and, in particular, those students who experience both physical and cognitive disabilities (Crewe & Zola, 1983; Weiner, 1986).

Today, the number of students with physical and multiple disabilities who are served in the public school system is rapidly increasing. This number will continue to grow as medical technology becomes increasingly able to promote the viability of infants with severe disabilities, as people with disabilities are deinstitutionalized, and as advocates increasingly assert for the rights of people with severe disabilities to live normalized lives. Recent federal legislation (Individuals with Disabilities Education Act, Public Law 101-476; Americans with Disabilities Act, 1990) has fueled formal commitments to enhance school and adult-focused efforts to promote the independence of people with disabilities.

As a result of recent initiatives, many students with physical and multiple disabilities now attend school in inclusive settings. By and large, inclusion has been a positive factor for these students (Brinker & Thorpe, 1984). However, students in inclusive settings may lack access to disability-related educational and related services designed to enhance their personal mastery and functional capabilities. Validated instructional strategies and adaptive equipment are, in many cases, available to enable students to perform these activities (Sowers & Powers, 1988b). However, the provision of such strategies and equipment to these students is often overlooked or difficult to accomplish within existing educational and related service support models. Furthermore, as students are fully included in typical classes, they often do not have incorporated within their school schedules opportunity to learn about disability-related information essential to their growing independence; information about getting around the community, identifying adaptations, self-advocacy, and managing personal service assistants.

## Personal Challenges

One of the most serious obstacles to the well-being, independence, and inclusion of youth with neuromuscular disabilities is the helplessness they experience. They are challenged by numerous physical limitations that restrict their strength, mobility, speech, dexterity, vision, endurance, and cognitive capabilities (Goldenson, Dunham & Dunham, 1978; Stopford, 1987). As a result, they often experience great difficulty performing functional activities and interacting with their environments. Many youth also experience significant health instability, requiring on-going medical care and exposure to procedures that may be uncomfortable, disempowering, and incapacitating (Steinhausen, Schindler, & Stephan, 1983). To obtain assistance with personal care and daily activities, students with physical and multiple disabilities often use support provided by others. However, typically they are passive recipients of such support (Ulicny, Adler, & Jones, 1988). The prevalence of architectural and communication barriers further exacerbates the dependence of youth with significant physical disabilities (Cruickshank, 1976; Scherer, 1988), as do negative societal and professional attitudes regarding their worth and potential for achievement (Edgerton, 1967; Fichten, 1988; Goffman, 1973).

Evidence also indicates that children with severe physical disabilities often fail to develop the mastery motivation necessary to enable them to make choices and to attempt behaviors that will maximize their functional independence and self-confidence (Lindemann, 1981; Robinson & Robinson, 1976). This occurs as a function of parental overprotectiveness (Cruickshank, 1976; Kessler, 1977), reinforcement of passive behavior by teachers (Downing, 1988) and medical care providers (Lewis, Pantell, & Sharp, 1991), and through restricted access to role models with disabilities (Rousso, 1988) and nondisabled peers (Mitchell, 1988) who serve to reinforce self-confidence and effective strategies for coping with challenge. Additionally, teachers and other school personnel often lack the necessary skills to enhance the perceived competence, social skill development, and functional abilities of such students (Brown, Pumpian, Baumgart, Vandeventer, Campbell, 1989; Honig, 1986; Neistadt, 1986), or to effectively impact the expectations of their parents (Espinosa & Shearer, 1986). Simply put, many young people with physical and multiple disabilities become locked into attitudes and patterns of behavior that include passivity, expectation of failure, depressed affect, and resistance to new challenges (Jones & Ulicny, 1986; Lindemann, 1981).

There currently exists strong national initiatives to provide students who experience disabilities with the skills that they need to lead lives which are meaningful, productive and inclusive. Normalization has become defined by community presence, choice, competence, respect, and community participation (O'Brien, 1987; Wolfensberger, 1972). The development of independent living programs and employment supports have provided new opportunities for persons with physical disabilities to live increasingly inclusive lives. Unfortunately, the learned passivity exhibited by many youth who experience physical challenges constitutes a significant obstacle to both their success in inclusive environments and their independence and self-competence. These students are at risk for failure to acquire the necessary functional capabilities to enable them to perform independent living skills at their maximal level of competence and to succeed in living environments that emphasize the promotion of independence and active direction of support. They are also likely to experience depression, social isolation, and low self-esteem (Robinson & Robinson, 1976; Turner, & Noh, 1988). Finally, by virtue of their failure to develop skills such as assertiveness, choice-making, problem-solving, advocacy, and perseverance, these students often have difficulty functioning in integrated environments and exhibit (1) poor social skills, (2) lack of active involvement with social support and peer relationships, and (3) and impaired achievement motivation and sense of personal mastery (Lindemann, 1981; Schalock & Harper, 1978).

## The Mastery Project: A Validated Approach to Address the Need

Validated methods to optimize the independence, and self-confidence of students with physical and multiple disabilities must be integrated into feasible models of inclusive educational support. Such approaches should be systematically designed to reduce student actual and perceived learned helplessness. Evidence indicates that this goal can be achieved through the implementation of student-focused procedures to enhance mastery orientation, independence and autonomy (Harter, 1981, Turnbull Turnbull, Bronicki, Summers, & Roeder-Gordon, 1988; Wehman, Mood, Everson, Wood, & Barcus, 1988).

Over the last three years, we have developed, implemented, and field-tested in Oregon a comprehensive model (OSERS Grant # H086D90001; entitled "The Mastery Project") to enhance the inclusion, independence, and self-confidence of middle school and high school students who experience physical and multiple disabilities. The model, publicly known as "RISC (Reach for Independence and Self-Confidence)" is designed to enhance independence and inclusion by providing students with experiences that promote their development of mastery motivation and self-efficacy. The model has been collaboratively implemented by school districts and independent living programs. While most existing models to enhance student independence and inclusion rest on either parent-directed support to the student (e.g., Dudley, 1980; Markel & Greenbaum, 1981) or instructor-directed intervention (e.g., Belamy, Horner, & Inman, 1979), the RISC model has as its centerpiece student-directed participation in inclusive activities in school, community, and home settings. Students learn that they are responsible for promoting their own independence and inclusion, and are exposed to specific strategies to identify and achieve their personal inclusion goals. The major components of the model include (a) instruction in, and in-situ application of generic strategies to set goals across domains of school life, home and community life, and friendship, identify and solve disability-related challenges, plan activities, and manage personal support; (b) promotion of family capability to support the developing independence of the student; and (c) enhancement of student access to support and information from peers and adult mentors who also experience disabilities.

*Because the model is student-directed, much of the responsibility for implementation rests with students, with staff acting as facilitators for student participation in model components.* As such, the model has two major advantages over existing parent or teacher-directed approaches. First, RISC promotes student self-perceptions of personal competence by providing opportunities for students to witness their success as they act on their own behalf. Second, RISC requires less intensive staff involvement because it focuses on systematically teaching youth generalized strategies for performing a variety of activities rather than providing repeated specific activity-based training. These advantages also make RISC ideally suited for delivery to students in inclusive settings because it does not require extensive involvement in resource intensive, exclusive pull-out programs and facilitates access to "natural" environments where students can apply their skills.

## (B.) Conceptual Framework

This section will present a theoretical and empirical basis for our conceptualization of the factors, depicted in Figure 1, that influence the mastery orientation of students with physical and multiple disabilities. The information presented has been derived from the work of leaders in the field of independent living, special education, and psychology and from our own experiences in delivering services to students with physical challenges.

### Learned Helplessness

Learned helplessness is an acquired behavioral disposition characterized by passivity, self-denigration, and internalization of devalued social status (Seligman, 1975). It is induced through repeated failed attempts to impact the environment. A child who experiences repeated failure is likely to avoid new challenges. Zeaman and House (1960) demonstrated the pervasive effect of failure in a study of adults with cognitive disabilities. Participants were initially presented with a task that they completed with ease. Subsequently, they were asked to complete an insolvable problem. Following failure on this task, the easy task was reintroduced. Results indicated that participants had great difficulty completing the easy task following their failure experience. They demonstrated a tendency to react to failure by withdrawing and ceasing to try. Learned helplessness is associated with reduced autonomy and impaired problem-solving (Luchow, Crowl, & Kahn, 1985; Margalit & Shulman, 1986; Peterson & Stunkard, 1989). Students who experience physical disabilities are constantly confronted by tasks that are difficult to perform, often have high potential for failure, and must exhibit perseverance if success is to be achieved (Allsop, 1980; Davis, Anderson, Linkowski, Berger, & Feinstein, 1985; Fielder, 1988). As such, they are highly susceptible to developing learned helplessness unless they are provided with methods to enhance their success.

Learned helplessness is perpetuated and reinforced by environmental factors that encourage passivity by providing little opportunity for an individual to actively make choices and generate successful responses, by communicating expectations of non-involvement or failure, or by reinforcing failure or not reinforcing striving (Houghton, Bronicki, & Guess, 1987; Hoy, 1986). Inadvertently, parents and teachers often act as the primary environmental influences in promoting student helplessness. Parents often encourage passivity through overprotection (Cruikshank, 1976; Kessler, 1977), excessive management (Lindemann, 1981), lack of knowledge about how to involve child in activities (Espinosa & Shearer, 1986), or due to difficulty in coping with the child or other life stress (Turnbull & Turnbull, 1986). Direct observation of parents interacting with their children with disabilities indicates that they manage the behavior of their disabled child more frequently than do parents of nondisabled children. They also provide less opportunity for their disabled child to initiate behavior and treat them more passively than their nondisabled children.

School staff may encourage student passivity by failing to utilize best-practice technology to assist students to perform at their optimal level of independence. Often direct service staff are undertrained in the use of standard instructional technology (Brown & Hughson, 1989; Brown, Pumpian, Baumgart, Vandeventer, Ford, Nisbet, Schroeder, Gruenwald, 1981), or they do not perceive the applicability of validated instructional methods for instructing persons with physical challenges (Sowers & Powers, 1988a). Furthermore, many professionals are unaware of specific training strategies that can be used to enhance motor skills of students with neuromuscular disabilities. Traditionally, motor skill acquisition has been considered to be within the realm of physical therapy, and teachers have been hesitant to teach functional skills that required training movements. School and community staff reluctance to use this technology has, in effect, severely restricted the range of instructional focus in the classroom and community for children with neuromuscular disabilities. The opportunity to utilize motivation-enhancing reinforcement has also been reduced because these children perform fewer behaviors for which consequation is directed.

## Mastery Motivation

In contrast to learned helplessness, a model of mastery motivation proposed by Harter (1981) provides a framework for understanding how youth acquire a generalized positive disposition toward achievement and striving. Mastery motivation is characterized by perceived competence, self-esteem, maintenance of an internal locus of control, and internalization of goals and rewards. It is achieved through repeated attempts paired with reinforcement for successes. Students who possess mastery motivation exhibit a demonstrated willingness to expend effort in domains that are historically success associated. Such children try hard to achieve goals and often succeed more often than do children who lack such motivation (Clark, 1980).

Parents who encourage mastery motivation set goals that are slightly beyond the present capabilities of their child; they do not require too little of their child and thereby reinforce passivity, nor do they demand too much and thereby set the stage for failure (Lindemann, 1981). As children move through adolescence and young adulthood, their parents encourage them to set their own goals, to take acceptable risks and to self-advocate (Singer, Todis, & Powers, 1990). Likewise, school staff facilitate mastery motivation by providing clearly defined rules that are enforced, high levels of engagement, frequent feedback, and contingent reinforcement (Brophy & Good, 1974; Englert, 1983, 1984; Rosenshine, 1979).

## Self-Efficacy Expectations

Bandura's theory of Self-Efficacy provides additional understanding of the influences that impact the development of mastery orientation. According to Bandura (1977; 1986), behavior depends on both outcome expectations and personal efficacy expectations. Outcome expectations consist of beliefs about whether a particular behavior will lead to a particular consequence. Personal efficacy expectations refers to a person's expectation regarding his or her capability to realize a desired behavior in a specific context. It does not reflect a person's skills, but rather one's judgment of what one can do with whatever skills one possesses. This distinction is particularly salient for students with physical and multiple challenges, because it provides a mechanism whereby they can perceive themselves as self-efficient despite their numerous physical, cognitive, and sensory limitations.

There is a growing body of evidence that self-efficacy beliefs are an important predictor of academic success (Graham & Harris, 1989), motivation (Schunk, 1989), and functional well-being (Dolce, 1987) for people with disabilities and health challenges. Self-efficacy beliefs are impacted by four specific sources. The first source is **performance accomplishments.** There is general agreement in the field regarding both the importance of functional skill acquisition for enhancement of child autonomy and quality of life, and the ability of children to learn functional skills in various contexts (Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenwald, 1979; Sowers, Rusch, Connis, & Cummings, 1980; Wilcox & Bellamy, 1987; Wehman, 1981). Research indicates that children typically perceive their achievement in two primary domains: task-related and social (Harter, 1981). This dichotomy becomes even stronger as adolescence approaches and youth become focused on peer group relations and performance of autonomous activity (Schinke & Gilchrist, 1984). There is also some evidence to indicate that task-related competence is a determinant of social achievement, i.e., performance is predictive of social acceptance (Gottlieb, Semmel, & Veldman, 1978). Thus, it is important to design strategies that enhance self-efficient expectations in task-related and social contexts.

For students with physical challenges, this involves the creation of specific opportunities in which they can experience success through achievement. Such opportunities are created by providing students with activities that they deem important and can successfully perform or participate in performing. Often the most significant obstacles to the performance of tasks by students with neuromuscular and health-related disabilities are physical problems such as inability to manipulate objects, limited communication ability, restricted mobility, incontinence, pain, drooling, and difficulty eating and drinking (Sowers, Jenkins, & Powers, 1988). For this reason, special attention must be directed toward decreasing the functional impairment created by these problems when attempting to facilitate the self-efficacy of such individuals.

**Vicarious learning** is a second source for the development of self-efficacy expectations, particularly in novel contexts with ambiguous task demands. This type of learning typically occurs in the course of contact with peers and other members of the individual's informal social network (Fewell & Vadasy, 1986). The importance of peer contact, for purposes of both enhancing social skill development and quality of life is echoed across the field of special education, and is associated with both vicarious learning and enhancement of social support (Brown et al, 1979; Wehman, 1981; Wilcox & Bellamy, 1982). Role models are another source of vicarious learning. Through exposure to successful role models, students with physical challenges have an opportunity to learn and practice disability-related strategies for overcoming obstacles and develop personal identity and pride (Rousso, 1988).

A third source that contributes to perceptions of self-efficacy is **verbal persuasion**. People who are persuaded verbally through encouragement are more likely to expend effort to strive for an outcome. Evidence indicates that students who are provided with opportunities to make choices and attempt skills with potential for success, to engage in problem-solving, and who are reinforced for their attempts demonstrate motivation and success in learning (Brophy & Good, 1974; Lindemann, 1981).

The final source of self-efficacy expectations derives from **physiological information** available to the individual (Bandura, 1986). In particular, heightened arousal is associated with expectancy for failure and, consequently, lowered self-efficacy. For example, having shaking hands during a typing task may cause an individual to expect that he or she will be unable to type well. The role of physiological arousal has significant applicability to the experience of students with neuromuscular disabilities, such as cerebral palsy. Physiologic arousal is often heightened dramatically for these students any time they attempt a movement. As a result, they are continually provided with physical feedback that indicates they do not have control over the muscles that they need to use to perform tasks. Techniques such as relaxation training can be used to both increase motor control (Sowers & Powers, 1991) and to positively impact the student's self-efficacy expectations. Likewise, sensations of physiological well-being associated with effective medical self-management also promote self-efficacy expectations of youth with chronic health challenges.

## Summary and Implications

There is theoretical agreement and empirical support for the notion that the promotion of mastery motivation and self-efficacy expectations will enhance mastery orientation. The development of these characteristics in young adults with physical disabilities and chronic health challenges is promoted by: (a) opportunity to perform activities successfully, (b) exposure to sources of vicarious learning, (c) encouragement from others, and (d) positive physiological feedback. As such, mastery orientation will be promoted through exposure to environments that provide viable opportunities to proactively respond, emphasize participation and success, and reinforce striving.

## Mastery Orientation: Domains of Influence

Research indicates that children typically perceive their achievement in two primary domains: task-related and social (Harter, 1981). This dichotomy becomes even stronger as adolescence approaches and youth become focused on peer group relations and performance of autonomous activity (Schinke & Gilchrist, 1984). There is also some evidence to indicate that task-related competence in school settings is a determinant of social achievement (Gottlieb, Semmel, & Veldman, 1978). Thus, it is important to implement strategies that enhance mastery orientation in task-related and social contexts.

### Task-related contexts

Task-related mastery orientation in students with physical and multiple disabilities can be promoted in two major ways. The first involves the direct maximization of the student's ability to perform targeted activities. The second involves indirect enhancement of the student's capabilities by providing instruction and coaching in generic skills essential to the student's independent task mastery.

#### Direct Intervention

This goal can be effectively accomplished through the identification of moderately challenging tasks of functional importance, and the provision of systematic training, reinforcement, task design modifications, and adaptations. It is critical that tasks be trained across functional domains : specific activities within educational, community, residential, and social environments must be individually targeted based on the student's present goals and future plans (Halpern, 1985; Wilcox & Bellamy, 1987).

Once activities are identified, training, adaptations, and support can be provided to optimally enable the student to participate in each activity. Sowers and Powers (1990) describe this process as "overcoming the performance gap". According to this notion the goal of providing training, adaptations, and support is to assist the student bridge the gap between the requirements of the activity and the student's current ability to execute the movements and discriminations necessary to perform it. Validated instructional methods can be systematically utilized to train the discriminations and motor behaviors necessary to perform tasks (Bellamy, Horner, & Inman, 1979; Martin, 1989; Sowers & Powers, 1988a). The efficacy of such training is well-documented in the literature across contexts.

## Indirect Enhancement through Generic Skill Building

There is general agreement that instruction in generic skills such as goal-setting, problem-solving, activity planning, assertiveness, and self-management enhances independence and self-competence. (Clark, Mack, & Pennington, 1988; Glueckauf, Horley, Poushinsky, & Vogel, 1984; Grimes, 1980; Starke, 1987; Summers, 1986a; Varela, 1986). Students with physical and multiple challenges must also learn methods to direct personal support.

### Goal-setting

Evidence indicates that instruction in goal-setting is an effective method to promote independence and inclusion for teenagers with physical disabilities (Sherman, Berling, & Oppenheimer, 1985). It important for young adults with physical disabilities to learn to select goals that they perceive as challenging and use strategies to ensure that their efforts result in perceptions of positive outcomes. Such positive perceptions can be fostered by monitoring achievements, learning to value trying over achievement of a particular outcome, and placing value on achieving goals that are valued and realistic. Those assisting the student in goal attainment, in turn, can use strategies to enhance achievement, such as modifying the task or the social norms, providing assistive devices, shaping, and partial participation (Sowers & Powers, 1991).

### Problem-Solving

Evidence indicates that persons with disabilities can effectively apply problem-strategies if they are provided with systematic, in-situ training (Hughes & Rusch, 1989). Problem-solving skill, although indispensable, is particularly difficult for many young adults with physical disabilities. One reason is because they often have a history of limited access to life experiences and information about solution options (McCarthy, 1986). As a result, they often need assistance identifying their requirements and potential solutions. A second reason is that, in order to attempt solutions, these young adults often have to enlist physical assistance, obtain assistive equipment, or receive specific training in order to execute the response. This is often problematic for adolescents who are, at the same time, attempting to strengthen their perceptions of personal autonomy and independence (Lovett, 1985). Students must be both encouraged to select solutions that minimize their reliance on others and empowered to proactively request and manage technical assistance from others with specific expertise.

## Assertiveness

Assertiveness training has been used widely with nondisabled populations and has been shown to be effective for individuals with disabilities (Granat, 1978; Grimes, 1980; Heimberg, Montgomery, Madsen, & Heimberg, 1977). Skills such as establishing positive body language, communicating clearly, using stop action communication techniques, and managing other's resistance are important components of assertiveness (Jakubowski & Lange, 1978). Individuals with physical and multiple disabilities have additional problems exhibiting assertive behavior due to communication and movement difficulties (Glueckauf, Horley, Poushinski & Vogel, 1984; Sowers & Powers, 1989). As such, they require specific strategies to effectively and assertively communicate their wishes. Evidence indicates that youth with physical disabilities can learn assertiveness skills if provided with specific training (Starke, 1987).

## Self-Management

Self-Management refers to the ability of an individual to monitor his or her behavior, self-attribute, and contingently reward him or herself for successful performance of a specific activity (Workman, 1982). Self-management is associated with enhancement of personal empowerment, autonomy, and internal locus of control (Brigham, 1989a; Williams & Long, 1979). There is a growing body of literature that indicates that feedback such as self-talk is effective in assisting people to shape their own behavior (Dush, Hirt, & Schroeder, 1989). The effectiveness of reinforcement methods for assisting persons to accurately perform activities is also well-substantiated (Bellamy, Horner, & Inman, 1979). Evidence indicates that the learned helplessness of adolescents with disabilities is exacerbated by noncontingent rewards (Kleinhammer-Tramill, Tramill, Schrepel, and Davis, 1983). Accurate self-monitoring, self-feedback, and contingent delivery of valued rewards by young adults with disabilities appears to provide an effective method to enhance mastery orientation.

## Management of Personal Care

Students with physical disabilities must learn how to actively manage the assistance they receive from others. The student's ability to direct his or her support is essential, given the poor skills and limited training that many support providers possess (Slagle, 1982; Smith, 1981; Stelmach, Postman, Goldstein, & Shepard, 1981) and the individualized needs of students with physical disabilities (Fewell & Vadasy, 1986). Providing students with methods to direct the assistance that they receive will enhance their feelings of independence and perceptions of self-efficacy, and facilitate their ability to supervise assistants as adults (Vash, 1981). Evidence in the independent living literature indicates that consumer-directed personal service assistance is associated with enhancement in consumer activity, quality of life, and consumer ability ratings (Pennsylvania Evaluation Report, 1986). In fact, access to and effective management of personal care services is considered by some to be the most important facet of independent living for adults with physical disabilities (DeJong & Wenkler, 1983). Students and young adults who are able to direct their care through active participation and management are likely to both feel a sense of added control over their lives, and to experience a higher quality of life (DeJong, 1979; Sailor, Gee, Goetz, & Graham, 1988; Ulicny & Jones, 1987). Thus, for reasons of preparation and empowerment, it is critical that students with disabilities learn to assume control for the direction of their support.

## Social Contexts

Social support networks typically provide esteem support, informational support, social companionship, and instrumental support (Cohen & Wills, 1985). Mastery orientation can be fostered within informal and formal social networks. Informal social networks are primarily constituted by peers, family, and role models. Formal social networks usually consist of school and community support personnel. Evidence indicates that participation in positive social interaction is associated with enhancement of skill development, self-image, social development, and self-esteem for students with disabilities (Bricker, 1978; Gresham & Elliot, 1987; Kozlowski, 1983; Patton, 1985).

### Peer relationships

With regard to peer relationships, there is general agreement that positive interaction between students who experience disabilities and nondisabled students is critical for effective community integration, and promotes the well-being of all involved (Bricker, 1978; Gaylord-Ross, Haring, Breen, & Pitts-Conway, 1984). Two major models to stimulate such interaction have been validated. The first, peer tutor interventions (Odom & Strain, 1986; Strain & Odom, 1986), utilize nondisabled peers to provide training and friendship to students with disabilities. The second, social interaction interventions (Voeltz, Hemphill, Brown, Kishi, Klein, Fruehling, Levy, Collie, & Kube, 1983), encourages the development of friendship-based relationships among disabled and nondisabled peers through joint participation in mutually enjoyable activities. Such activities may include sharing a pizza, playing video games, or listening to music.

Although no definitive evidence exists to support the effectiveness of one intervention over the other (Haring, Breen, Pitts-Conway, & Gaylord-Ross, 1987; Voeltz, 1982), many argue that social interaction interventions are superior because they promote horizontal relationships and reciprocity (Cooley, 1989; Voeltz, 1980). Furthermore, evidence indicates that equal status contact is an important factor for the development of both positive attitudes toward individuals with disabilities by others and positive self-perceptions of persons with disabilities (Fichten & Amsel, 1986). The effectiveness of peer support and advocacy groups in the community of persons with disabilities also highlights the importance of equal status and shared goals for the development of peer networks (Smith, Fawcett, & Balcazar, 1991).

## Parents and Teachers

In association with student-focused intervention, attention must be directed toward modifying the attitudes and behaviors of parents and school staff that encourage youth passivity and helplessness. (Fewell & Vadasy, 1986; Mitchell, 1988). Teachers must be willing to provide youth with access to information and experiences that will promote their decision-making and convey confidence in their abilities to make effective judgments (Mitchell, 1988). In addition, school staff must be provided with facilitative strategies to use for establishing cooperative relationships with parents (Goetz, Anderson, & Laten, 1989; Slater, Martinez, & Habersang, 1989; Walker, 1989).

Methods designed to enhance the abilities of parents to support the mastery orientation of students must provide: (a) acknowledgment of the ways in which parents successfully support their children (Summers, Behr & Turnbull, 1989); (b) training in the use of facilitative techniques such as praise, encouragement, and emphasizing strengths. (Singer, Irvine, & Irvin, 1989); (c) exposure to information that positively impacts their awareness of resource options and their attitudes regarding the functional competence of children and adults who experience physical disabilities (Kornblatt & Heinrich, 1985; Sowers, 1989); (d) opportunity for parents to expose their youth to functional activities in which the student is encouraged to take risks and provided with choices and responsibilities (Fredricks, 1988; Mitchell, 1988; Moon & Beale, 1984); (f) involvement in cooperative planning with the student to maximize his or her independence and inclusion (Halvorsen, Doering, Farron-Davis, Usilton, & Sailor, 1989; Kohr, Parrish, Neef, Driessen, & Hallinan, 1988; and (g) support to assist parents to adjust to the autonomous activities of their disabled child (Espinosa & Shearer, 1986; Intagliata & Doyle, 1984; Singer & Irvin, 1989).

## Role Models

The importance of role models for shaping attitudes, interests, and aspirations of youth is generally acknowledged (Garfield & Bergin, 1986; Gottlieb, 1981). Likewise, role models are considered significant for the development of self-esteem, positive view of disability, and living skills for youth with disabilities (Fredericks, 1988; Jones & Ulicny, 1986). As an indirect effect of inclusion, youth with disabilities often have little contact or opportunity to develop positive relationships with older, more experienced persons who also have disabilities. As a result, many young people begin to doubt their abilities to successfully overcome disability-related barriers to independence. Recent evidence suggests that interaction with adult role models who experience physical disabilities enhances (1) the disability-related knowledge and self-confidence of adolescents with physical disabilities, and (2) parent perceptions of the knowledge and capabilities of their children with disabilities (Powers & Sowers, 1992).

### Implications

To facilitate the mastery orientation of youth who experience physical and multiple disabilities, it is critical that methods be developed to enhance student mastery motivation and self-efficacy. This can be accomplished by providing youth with experiences that enhance their functional capabilities in task-related and social domains; experiences such as training and adaptations, in-situ instruction in generic independence skills; facilitation of contact with peers and role models; and support to enhance the capabilities of parents to promote their functional capabilities and self-confidence.

## IV. MODEL AND PARTICIPANTS

### (A.) Model Components

The purpose of The Mastery Project was to develop and demonstrate methods that school districts could use to enhance the mastery orientation of students with physical and multiple disabilities. During three years of model development and refinement, several methodological and logistical modifications were undertaken. The rationale for, and nature of these modifications are described in Section VII.. The purpose of this section is to describe the refined model as implemented during Year 3 of the project. In reality, the model continues to be refined and field-tested following the cessation of funding provided through the Mastery Project. The investigators conceive of the work accomplished during the Mastery Project as laying the foundation for the further development and validation of a very comprehensive approach to facilitating mastery orientation and functional competence of adolescents with physical and multiple disabilities.

The refined model includes the following major components:

(1) Student-directed assessment, instruction in, and in-situ practice of generic independence skills at school, at home, in the community, including friendship development goals.

(2) Participation in mentoring and peer support activities.

(3) Enhancement of the ability and willingness of parents to support student mastery orientation.

Component One: *Student-directed assessment, instruction in, and in-situ practice of generic independence skills at school, at home, in the community, including friendship development goals.*

Students are provided with instructional coaching and have the opportunity to practice a step-by-step process for assessing independence, setting goals, creatively solving problems, planning activities, and self-managing their behavior through participation in "Steps to Independence" curriculum-based instruction. This instruction serves as the centerpiece around which other RISC components are structured. The development and utilization of a "Steps to Independence" curriculum facilitates fidelity of implementation, independent study, and dissemination. Students apply the procedures they learn to accomplish specific inclusive activity goals. They are also provided with in-situ opportunities to practice assertiveness, coping, and advocacy. Additional opportunity to learn and practice these skills is provided in Component Two.

Students also receive training in specific strategies that they can use to manage the personal assistance that they receive from others. Training is based on the work of experts in the Independent Living Movement (Ulicny, Alder, & Jones, 1988; Ulicny, Elwell, & Jones, 1984; Ulicny & Jones, 1985). These two experiences will now be described.

## Steps to Independence Instruction

Students are provided with a self-help guide entitled "Steps to Independence". The guide is included in Appendix A. Students who have difficulty reading or learn best by listening are provided with audio tapes of each chapter. Each chapter provides an introduction to the importance of the skill and examples of applications of the skill to achieve different categories of school, home, friendship, and community activity goals. The chapters are designed interactively by interspersing questions and structured exercises the student can complete to self-evaluate the extent to which s/he is learning the material.

The application of each skill is presented as a series of generic steps. By learning generic steps, students acquire a standard framework for applying each skill across a variety of contexts. Systematic procedures are utilized to promote student acquisition and application of each step. This approach facilitates student learning and generalization of skills. Additionally, it promotes application of methods to any activity goals students select and does not constrain their choice of goals.

## Goal Identification and Selection

A list is developed that includes activities from school, community, and home contexts that (a) the student does not perform or performs with low levels of independence, (b) there is a reasonable expectation that the student's level of participation or independence can be enhanced, and (c) are typically performed by youth of his or her age group. Preference is given to activities that are not performed due to problems with mobility, vision, hearing, communication, incontinence, drooling, eating and drinking, and poor manual dexterity.

The list is derived from the results of **Functional Skills Assessments** that are cooperatively completed by the student and his or her parent (for home and community activities) and the student and his or her teacher (for school activities). The assessments, included in Appendix B., consist of a series of questions designed to determine the extent to which the student performs specific functional activities at home, in school, and in the community. The assessment focuses on the "step" level. This focus is necessary in order to accurately determine the student's current nature of physical participation and to formulate potential strategies to enhance the student's independence.

Student goal selection is performed in conjunction with instruction in the goal-setting chapter of the "Steps to Independence" curriculum. The student reviews the activity list generated by the Functional Skills Assessment, and selects 2-3 activity goals in each context that he or she would like to perform more independently. Examples of student goals are listed below.

| Home | School | Community |
|---|---|---|
| 1) Use the phone | 1) Use my locker | 1) Do my own banking |
| 2) Make a snack | 2) Get my own lunch | 2) Go clothes shopping |
| 3) Do laundry | | 3) Eat at fast food restaurants |

Following the student's identification of activity goals, a meeting is scheduled during which the student shares his/her goals with his/her parent, designated school staff, and staff from the Independent Living Program. This usually occurs in the student's IEP meeting. The primary purpose of the activity is to create a in-situ opportunity for the student to demonstrate independence, assertiveness, and personal autonomy. Prior to the meeting, the student rehearses methods to present goals, explain rationales for goals, and assert the importance of pursuing goals if s/he faces challenges from those present at the meeting. Following presentation of goals, the student explicitly requests the support of everyone involved.

## Instructor Facilitation

Students apply the procedures they learn to accomplish their specific, self-selected activity goals. To facilitate learning and application of the material, each student meets weekly with an educational facilitator from his/her school. Facilitators included teachers, related service staff, guidance counselors, or inclusion specialists. The Facilitator's Guide is included in Appendix B.. Facilitation meetings are conducted at a time convenient to the student's schedule. For many students attending inclusive educational settings, facilitation is provided during a study hall, guidance session, or integrated into the student's participation in other classes such as health or social studies. As required to ensure successful application of strategies, in-situ facilitation may also be provided in the context in which the student is performing the activity. Students are given credit for their participation in facilitation classes.

Facilitators promote student learning and application of strategies using a variety of methods. These approaches may include review of material the student is learning, providing instructional adaptations to facilitate learning, helping the student problem-solve solutions to barriers that may arise, and providing systematic training or arranging for training to be provided by other resource staff at the school. To provide the student with effective "technical assistance" to accomplish steps of desired activities, it is necessary to determine what training strategies could be used and adaptive strategies devised to assist a student to perform the skills/behaviors required by each option. Staff attempt to identify as many different training or adaptive strategies which could be used to enable a student with a physical and multiple disability to perform a targeted activity goal. Table 1 provides guidelines for categorizing and selecting adaptation strategies. Such strategies may combine specific adaptations with partial participation (Baumgart, Brown, Pumpian, Nisbet, Fort, Sweet, Messina & Schroeder, 1982).

---

Table 1: Guidelines for Selecting Adaptation Strategies for Students with Multiple and Physical Disabilities

**Six Types of Adaptation Strategies:**

1. Alternative Movement Strategies
2. Commercially Available Assistive Devices
3. Non-Commercially Available Assistive Devices

4. Eliminate Difficult Steps
5. Rearrange the Environment
6. Support/Assistance from Another Person

**Steps in Selecting Adaptation Strategies:**

1. Identify the specific motor movement problem
2. Identify the array of possible adaptation strategies which could be used to help the student overcome the problem
3. Select the strategy which is the least intrusive and most effective
4. Institute the adaptation with training
5. Assess the extent to which the strategy is effective
6. Modify the strategy, or try another one if the original one is not effective

---

Training, adaptations, and support are then provided to maximize the students success in each activity. This is the most critical activity because the extent of success that the student experiences in performing the activity will often be a direct function of the quality of training, adaptations and support provided (Sowers, Jenkins, & Powers, 1988). Training strategies are also utilized by school staff to enhance the discrimination and motor capabilities of students as they execute their school and community activities. Validated instructional technologies are employed (Bellamy, Horner & Inman, 1979) as well as specific strategies for enhancing motor control (Inman, 1979; Sowers, Jenkins, & Powers, 1988). Training is conducted in the context in which the skill is desired to maximize acquisition (Marchetti, Cecil, Graves, & Marchetti, 1984). Perhaps the most important strategy that students, parents and teachers are taught to use is shaping. Utilizing this principle, they learn to systematically increase their performance expectations for the student as he or she becomes progressively better able to approximate movements and behaviors.

## Facilitating Student Success in Achieving Friendship Goals

In order to enhance the social competence of physically disabled youth within their social networks, school and ILP staff (1) facilitate opportunities for interaction of youth with members of their nondisabled social networks at school and in the community, (2) provide strategies and technology to facilitate communication, particularly for students who experience sensory impairments, (Garner & Campbell, 1987), and (3) provide education and support to members of the student's social network to enhance their ability and willingness to interact with the student. The methods used to enhance peer interaction are consistent with evidence that supports the development of reciprocal, horizontal relationships through the promotion of social-interactive contact (Voeltz, 1982).

To facilitate friendship-based goal specification, students, school staff, and ILP staff gather information about formal and informal peer gatherings at school and in the community. Strategies include talking with students, observing social patterns, monitoring up-coming events, and obtaining information about clubs and sporting activities. Students and staff determine the type of interaction (ex. topic focused, physical, informal hang-around) conducted, general social climate, time of interaction, and the number of youth or adults typically involved in each setting. Table 2 provides examples of social opportunities and context information that may exist in a school.

Table 2: Peer Contact Sheet

| Opportunities | Time | Number of Students | Focus of Contact | General Climate |
|---|---|---|---|---|
| 1. Students gather at school store | 1:00-2:00 | 6-10 | Gossip, jokes, information | Friendly |
| 2. Jazz club group | M,W 8:00-8:30 | 5-8 | Listen & talk about jazz | Defined |
| 3. Recess | noon | 100 | Hang around, listen to music, talk | Unpredictable |
| 4. Journalism | M,T,F 3:00-4:00 | 20 | Various tasks | Task-focused but friendly |

Students then choose which settings they would like to join and strategies are developed to assist them to gain entry into those contexts. Such strategies may include enlisting the help of a peer member of the group or a peer family friend. A peer who participates in the interaction may be recruited as a "liaison" for the disabled youth. As such, he or she will be introduced to the individual, provided with information about the student's interests, abilities, and communication methods, and asked to be a buddy and to introduce the student to others. Another strategy may involve providing the student with information or items that will be of interest to other students. For example, the student who wants to become involved in the jazz club may be provided with some jazz records to play for his or her peers. Still another strategy may involve permitting a student to leave an inclusive class five minutes early with a buddy. Many peers are eager to accompany a student to his or her next class and this event promotes additional interaction.

In addition to developing methods to identify interaction opportunities and to promote entry to peers, significant attention is directed to facilitating communication between the peer with a disability and other peers. Functional communications systems are developed that respond to the requirements of the specific context where the student will interact with peers. For example, communications books and communications devices can be tailored to enable a student to talk about certain topics such as music, movies, and family members. Coaching is also be provided to the student to enhance his or her interaction. Such coaching is coordinated with social skills training being provided to the student.

Likewise, nondisabled peers are provided with information about the methods that the student uses to communicate and suggestions regarding effective strategies for talking with the student. This may involve orienting peers to the student's communication device, suggesting ways in which they can phrase questions to require short answers from the student, or training them to understand the meaning of particular gestures. In all cases, peers are provided with concrete, specific information that avoids labels and terms associated with disability. Such **information is imparted by the student** with assistance provided, as needed, by a peer liaison, a teacher, or a short written description.

## Management of Personal Care

As an element of goal assessment, selection, and pursuit, all students participate in instruction and in-situ practice of generic support management steps. **First, students learn to identify activities** in school and community environments in which some type of support is currently needed. Such activities may include using a bathroom in three different settings, putting a coat on, combing hair, pushing elevator buttons, etc. A list of such activities is developed based on observation by the student, discussion with personal care providers, and discussion between the student, teachers, therapists, and parents. Emphasis is placed on identifying support needs that the student will probably require throughout life. The student then selects activities that he or she would like to more actively manage.

**Next, students learn to identify exactly what kind of assistance they require** to perform each activity. Utilizing traditional task analytic techniques (Bellamy, Horner, & Inman, 1979), those steps of each activity that are performed by the student and the assistant in an identified setting will be detailed by the student and his/her facilitator. The steps are identified through repeated observation of the student and assistant performing the activities, with consultation provided by the physical therapist. An example of a support step analysis is shown below.

24

Transferring from chair to commode

1. I open seat belt
2. Helper swings foot pedals out
3. Helper plants right foot against my left foot
4. I place arms around helper's neck
5. Helper places arms around my waist
6. We count to three
7. I push up on count of three
8. Helper lifts me out of chair
9. Helper pivots me to commode seat
10. I hold handrail

**Third, students learn basic methods to direct helpers**. They learn how to initiate to an assistant that help is required. This can be accomplished through verbal requests, use of switch-based call systems (Guess & Siegel-Causey, 1985; Wuerch & Voeltz, 1982), gestures, etc., depending on the nature of the context and the student's functional abilities. Once the assistant is alerted, the student is trained to indicate, using an appropriate form of communication, the type of assistance needed. For nonverbal students, a communication sheet is constructed that includes symbols or names for each category of support that the student uses (e.g., drink, go to the bathroom, put coat on). Students learn to stop their helpers if they perform a step incorrectly. To promote student learning, assistants are coached to make planned errors and students are provided with prompting and reinforcement to enhance their accurate response. Issues related to hiring and managing attendants are addressed as the student moves toward transition.

Component Two: *Participation in mentoring and peer support activities.*

Interaction of students with disabilities with one another and successful adults who also experience disabilities is a powerful method to enhance student advocacy, problem-solving skill, knowledge about and desire to access resource options, positive self-attributions, and self-esteem (Jones & Ulicny, 1986; Patton, 1985, Powers & Sowers, 1991). In the RISC model, independent living staff use two approaches to facilitate contact. The first intervention, "Mentoring" provides opportunities for students to practice effective methods for applying conference and Steps to Independence skills through participation in community-based activities with adult mentors. The second intervention, " Peer Conferences", provides students with information, structured training, and support related to coping with disability, life options, disability-related resources, assertiveness, and advocacy.

## The Mentor Program

Students are introduced to an adult with a similar disability who is successfully living in their communities. The student and the adult participate in 8 community activities over the course of the school year. Each activity provides opportunities for students to observe their mentors successfully dealing with disability-related barriers and talk with their mentors about their personal goals, questions, and concerns. Students and mentors cooperatively select each community activity based on the students interests and questions about independent living. The Mentor Guide is included in Appendix C. Mentors are also coached to provide students with several specific experiences during the course of their involvement in activities. These experiences may include:

1. Visiting the mentor's home
2. Visiting the mentor at his/her place of paid or volunteer work
3. Doing an activity during which the mentor and student practice management of support
4. Using personal advocacy skills to obtain some service
5. Discussion of personal views of disability, personal strengths, goals, making friends, and steps to becoming independent
6. Visiting a community agency selected by the student
7. Doing a novel, fun activity selected by the student during which the mentor can emphasize the importance of trying new activities, taking "wise" risks, and perseverance.
8. An activity performed with the student's family that will provide an opportunity for discussion of the student's strengths and capabilities

Adult mentors are recruited by the independent living program. Recruitment efforts are directed toward local colleges and universities, community agencies involved with persons who experience physical disabilities, and key members of the disability community. All persons who express interest in acting as a mentor participate in a careful screening designed to elicit information regarding their attitudes toward disability, their level of independence, and their sensitivity and expertise regarding responding to the concerns of youth with disabilities, and their willingness and ability to commit to acting as a mentor. Following selection, mentors participate in a training program in which the purpose of the program and their responsibilities are carefully explained. They are be provided with basic communications skills training, guidance regarding how to interact with parents, and information about the topics to be covered in Peer Conferences. Mentors are instructed to both model how to deal with barriers and to encourage and reinforce students for their attempts.

Mentors and students notify program staff and parents of upcoming mentoring activities and present parents with a written activity plan prior to each activity. As necessary, assistance is provided to the mentor and the student to enable them to participate in desired activities. Following each activity, the mentor is provided with phone or personal contact debriefing regarding issues that arose during that activity and coaching to facilitate the success of the next activity. Students and mentors are encouraged to talk on the phone and are free to meet more frequently that twice per month, as long as they follow stated procedures. At the conclusion of the six-month mentoring period, mentors are provided with strategies to supportively end their relationships with students to prevent students from feeling abandoned. Those mentors and students who wish to maintain their relationships after the conclusion of the program are encouraged to do so by their own arrangement.

### Peer Conferences

Students and their mentors attend five conferences per year during which they learn about and discuss disability-related issues and options. Each conference is scheduled for three hours with a 30-minute break for informal sharing provided. Conferences are conducted in a support group format. There is general agreement that group-based interventions provide the best context for addressing adjustment to disability and facilitating disability-related empowerment (Paulson, 1984; Stephens & Haley, 1987).

Conferences are sponsored by the independent living program in cooperation with local school programs. The conference facilitator, a peer support staff from the ILP, acts as a moderator, structuring the discussion and providing information, challenge, and encouragement. Conference topics and activities are derived from the recommendations of experts in the field of disability (Crewe & Zola, 1983; Lasky, 1977; Livneh 1985; Stephens & Haley, 1987; and Vash, 1981, Varela, 1986), and our personal experience facilitating groups for adolescents with physical disabilities. Each conference is structured around a specific topic, beginning with a presentation of content information followed by personal sharing and discussion. Opportunity for students to share their accomplishments and challenges as they strive towards personal activity goals is also provided during each meeting.

### Component Three: *Enhancement of the ability and willingness of parents to support the mastery orientation of students.*

A program has been demonstrated to enhance the ability of parents to support the independence and autonomy of their children. The strategies used are based on the work of experts in parent support (Dunst, Trivette, Gordon, Pletcher, 1989; Fewell & Vadasy, 1986; Singer, Irvine, & Irvin, 1989; Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1988). **Parents are provided with monthly coaching** to facilitate their ability to encourage their child's involvement and responsibility in home and community activities.

Parents are initially **invited to participate in the student goal meeting** described in Component One. The purpose of this meeting is to review the findings of the functional skills assessment, enable the parent to hear the student's proactive presentation of activity goals, and to enlist parent involvement in assisting the student to become more participative, autonomous and responsible. The parent's perception of the obstacles that prevent the student from achieving greater competence are explored. Parental suggestions regarding the implementation of strategies to facilitate the student's achievement of goals is elicited. A plan is then developed to assist the parent, through support and coaching, to encourage and reinforce the student's successful participation in activity goals and practice of Steps to Independence skills.

Throughout model implementation, **contact is maintained** with parents to elicit their ideas for school-based interventions and to provide information, assistance, and support for parent-based interventions. This contact takes the form of scheduled meetings, informal phone calls between parent and teacher, or home visits, as a function of the parent's preference and the nature of the specific issue addressed. This type of contact flexibility is considered to be more responsive to practical demands and more likely to enhance parent comfort and involvement than are large, structured meetings (Turnbull, & Turnbull, 1986).

Parent coaching is also provided in the context of three home visits during which the student's home activity goal(s) are observed, strategies to enhance the student's independence identified, and student-parent communication promoted. Short bulletins, publications, and information sheets that focus on strategies to facilitate child independence are also sent to the parent on a bi-weekly basis. This material, incorporated within a Parent Guide, is presented in Appendix D. The major emphasis for parent coaching is assisting the parent to identify specific independent living activities, in addition to those targeted by the student, in which the student could more actively participate and providing the parent with strategies to enhance student involvement.

Identified independent living activities may include chores, selecting clothes to wear, banking, recreational experiences, using the phone, or managing a personal schedule. The parent is provided with tips for the use of adaptations, support, and reinforcement to enhance student participation. The objective of providing tips to parents is not to turn them into trainers, but rather to design the activity such that the student has an opportunity to be more successful, the parent has an opportunity to view the student's success, and the parent has some guidelines for supporting and encouraging the student. It is the teacher's ability to provide the parent with useful, practical tips in conjunction with encouragement and guidance that most impacts on the parent's ability to support his or her child (Lavelle & Keogh, 1980).

A critical component of coaching is the validation provided to the parent regarding the student's progress and the positive effect of the parent's encouragement. Concerted effort is made to shift the focus of parent attention from what the student can't do to what the student can do. Techniques such as charting student success on individual activities, keeping a list of the various activities that the student participates in, and videotaping student participation are used to promote the attentional shift of parents. Parents are also encouraged to reinforce appropriate student risk-taking, to support the student's involvement in other Project experiences, to express their confidence in the student's abilities, and to involve the student in family advocacy activities. Support is provided to parents as they define parameters for their children's independence and adjust to the developing autonomy of their children.

## (B.) Participants

Participants in the Mastery Project included 10 students and their parents in Eugene, Oregon who attended the Eugene 4-J School District; and 20 students in Portland, Oregon who attended Portland Public Schools. Student ages ranged from 11-20 (mean = 16) and 40 % of the students were male while 60% were female. All but one of the students were wheelchair users and 74% experienced significant upper body impairment as well as lower limb impairment. The student who did not use a wheelchair used crutches, had restricted use of her hands, and experienced mild mental retardation. Fifteen of the thirty students involved in the project also experienced mild-moderate cognitive impairment. Nine students also experienced significant speech impairment. Thus, all students who participated in the project experienced severe physical disabilities and a majority experienced multiple disabilities.

The organizational participants in the Project in Eugene were Eugene 4-J School District and the Disabilities Advisory Coalition (DAC). The student facilitator in Eugene was a staff member from DAC. Portland Public Schools and Access Oregon collaborated to implement the Project in Portland. The student facilitators were two occupational therapists and a teacher from Portland Public Schools. Parent support was provided by student facilitators in both sites while mentoring activities were provided through the independent living programs.

# V. GOALS AND OBJECTIVES

The goals and objectives, as implemented in the Mastery Project are described below. Once again, it is important to note that the original goals and objectives of the Project underwent significant revision in response to challenges and opportunities encountered during implementation. These factors are detailed in Section VII. In all cases, revision to the goals and objectives was driven by the recommendations of our advisory panel and findings from formative and summative evaluation.

## (1) Development

### Objective 1: Prepare for Project Implementation

To conceptualize, write drafts of implementation procedures for each component, obtain input and feedback from the Advisory Panel, and identify the implementation districts.

Activity 1.1 - Formally Convene the Advisory Panel. The Advisory Panel was composed of the State Director of the Oregon Department of Educational Services for students with orthopedic impairments, a parent of a secondary-age student with physical and multiple challenges, a mental health professional with a severe physical disability, the Director of Transition Services for Eugene 4-J School District, the Director of Special Education Secondary Services for Eugene 4-J, and the Director of Lane County Direction Services.

Activity 1.2 - Conduct a review of existing literature, programs, curricula, and best practice procedures related to each component. We will perform a computer and manual search of all appropriate rehabilitation, special education, psychology, and ERIC data bases and journals to find relevant articles and books on independent living, self-determination, and personal assistant training, and psychosocial intervention strategies. We will also reviewed other guides and related materials (e.g., curriculum) for ideas related to product format. Finally, we reviewed other approaches to such issues as facilitating mentorship and advocacy.

Activity 1.3 - Develop and write drafts of the manual procedures. The purpose of this activity was to conceptualize the procedures and systems that were utilized to implement each of the components in an integrated fashion. We outlined each component of the manual. We then obtained feedback and input on the outlines from the Management Committee. Finally, we prepared first drafts of the manual procedures for use in project implementation efforts.

Activity 1.4 - Identify the first implementation district. Portland Public Schools served as our first implementation District.

Activity 1.5 - Negotiate agreements with Portland Public Schools for implementation of the model. This agreement specified a three-stage implementation, with project staff taking the lead during Year 1, District staff taking the lead during Year 2 with intensive Project support, and District Staff taking the lead during Year 3 with less intensive project support.

## (2) Project-Initiated Implementation and Field-Testing

Component activities were piloted during Year 1. The purpose of this phase was to identify the procedures and supports necessary to facilitate the successful implementation of each component by youth, mentors, parents, and staff. We will also field-tested the evaluation instruments to determine their reliability and validity during this phase.

### Objective 2: Conduct Pre-implementation Activities

During the remaining months of Year 1, we piloted the student facilitation and parent support components of the model, provided initial training to staff, and undertook substantial refinement and revision of the manual guides.

Activity 2.1 - Identify youth who will participate in Year 1.

Activity 2.2 - Obtain signed consents for participation in the project from youth, parent/guardians, and staff.

Activity 2.3 - Obtain basic functional information regarding each student who will participate in the project implementation. Information pertaining to the functional cognitive, health, and motor capabilities of each student, staff involved with the student, family status and contact information, and school/teacher name, and phone number will be collected for each student who will participate.

Activity 2.4 - Provide a half-day inservice to all staff who will be involved in pilot implementation.

### Objective 3 - Implement Model Components.

Activity3.1 - Identify all staff who will work with students and review the procedures to be used.

Activity 3.2 - Implement a system to facilitate student assessment, goal identification and achievement.

Activity 3.3 - Develop and implement methods for students to direct the assistance they receive.

Activity 3.4 - Develop and implement methods for students to identify and gain entry into intact peer groups.

Activity 3.5 - Develop and implement a system for individual mentoring and support conferences.

Activity 3.6 - Develop and implement methods for parent coaching.

Activity 3.7 - Provide bi-weekly information and support to parents.

Activity 3.8 - Meet with all staff involved in model implementation every two months to discuss issues, problems, and solutions related to implementation.

Activity 3.9 - Revise and refine the manual based on the results of Year 1 pilot activities.

### (3) District-Initiated Implementation

Components were implemented in Portland and Eugene during Year 2. District and independent living staff assumed primary responsibility for implementation with intensive support from the project.

Objective 4 - Prepare for Implementation.

Activity 4.1 - Identify the second implementation District.

Activity 4.2. - Negotiate agreements with the second implementation District.

Activity 4.3 - Identify students who will participate in District implementation activities.

Activity 4.4 - Obtain signed consents from students and parents.

Objective 5 - Conduct Year 2 District-Initiated implementation.

Activity 5.1 - Obtain basic functional information regarding each student who will participate in implementation.

Activity 5.2 - Provide a half-day inservice to all staff who will assume implementation responsibility.

Activity 5.3 - Identify all staff who will work with students and review the procedures to be used.

Activity 5.4 - Implement a system to facilitate student assessment, goal identification and achievement.

Activity 5.5 - Implement methods for students to direct the assistance they receive.

Activity 5.6 - Implement methods for students to identify and gain entry into intact peer groups.

Activity 5.7 - Implement a system for individual mentoring and support conferences.

Activity 5.8 - Provide parent coaching.

Activity 5.9 - Provide bi-weekly information and support to parents.

Activity 5.10 - Meet with all staff involved in district implementation every two months to discuss issues, problems, and solutions related to implementation.

Activity 5.11 - Revise and refine the manual based on the results of Year 2 implementation activities.

## (4) Field-Test of the Model

During Year 3, the model was implemented by Portland Public Schools with Access Oregon and the Eugene 4-J School District with the Disability Advisory Coalition. Local staff assumed primary responsibility for implementation with technical assistance and monitoring provided by the Project.

Objective 6 - Conduct District Implementation.

Activity 6.1 - Obtain functional information regarding each student participating in the Project.

Activity 6.2 - Provide a half-day inservice to all staff who will assume implementation responsibilities.

Activity 6.3 - Monitor quality and fidelity of implementation.

Activity 6.4 - Review district progress with staff on a monthly basis.

Activity 6.5 - Provide consultation and technical assistance as necessary to insure fidelity of implementation.

Activity 6.6 - Revise and refine the manual based on the results of Year 3 implementation.

## (5) Evaluation

Objective 7 - Identify and Develop Model-Focused Evaluation Instruments.

Activity 7.1 - Identify and develop instruments to measure mastery orientation.

Activity 7.2 - Identify and develop instruments to measure interaction with peers.

Activity 7.3 - Identify and develop instruments to measure student engagement in activities.

Activity 7.4 - Identify and develop instruments to measure direction of support.

Activity 7.5 Identify a measure of coping with disability.

Activity 7.6 - Identify and develop measures of parent support and involvement

Objective 8 - Develop Project-Focused Evaluation Instruments.

Activity 8.1 - Develop demographic measures. In order to document and clearly describe the Districts, ILP's, staff, mentors, and students who participated in the implementation. Comprehensive demographic measures will be developed and collected. This data will be collected prior to implementation in each District.

Activity 8.2 - Develop fidelity of implementation checklist. This instrument will be designed to measure the extent to which components prescribed by the model are implemented by and for each student. It will be used formatively to guide development, revision, and refinement of the components. It will be used procedurally to assist staff to facilitate accurate implementation of each component. It will be used summatively to evaluate the general extent in which the model was implemented. This will provide important information in conjunction with the student outcome data. The checklist will be completed using record reviews, staff interviews, and direct observation. It will be completed before implementation and at two month intervals post-intervention. Both traditional non-parametric statistical analyses and non statistical evaluation designs will be used to accomplish the summative evaluation of fidelity of implementation.

Activity 9.3 - Develop social validation indices. Three measures will be developed to assess the participants' perceptions of the usefulness of, and degree of satisfaction with, project activities. These measures will be administered to staff, mentors, and parents pre-implementation and post-intervention.

Objective 10 - Collect Data.

Activity 10.1 - Collect model-focused data.

Activity 10.2 - Collect project-focused data.

Activity 10.3 - Analyze data. Data will be analyzed qualitatively and quantitatively for the purpose of establishing the validity and reliability of the measures, determining the effectiveness of individual components and the model for enhancing student self-determination.

Activity 10.4 - Refine model and project-focused instruments based on findings. Findings from annual analyses of data will be used to refine the instruments and model, and shape dissemination efforts.

## (6) Model Dissemination

Objective 11 - Disseminate Project Materials and Findings.

Activity 11.1 - Write final project manual and activity guides.

Activity 11.2 - Present the model at local and regional conferences. Youth and consumers will be actively involved in dissemination efforts.

Activity 11.3 - Present approach and results to youth, consumer, parent, and community groups.

Activity 11.4 - Present the Model at national conferences.

Activity 11.5 - Submit project descriptions to ERIC and other data bases.

Activity 11.6 - Submit data-based articles from our evaluation activities to refereed professional journals.

Activity 11.7 - Provide materials to State of Oregon Department of Education, Mental Health Division, and Vocational Rehabilitation.

Activity 11.8 - Identify a publisher that will disseminate the materials nationally.

## VI. PROBLEMS AND SOLUTIONS

This section describes the major conceptual and logistical challenges experienced in project design and implementation, and the solutions adopted to address each challenge.

### A Conceptual Shift Toward Emphasis on Student Self-Direction

By far, the most critical shift undertaken by the Project involved re conceptualization of the Mastery Model from an approach to teach students skills and expose them to opportunities to an approach to facilitate student self-directed acquisition and application of skills. This shift was driven by detailed consideration of the self-efficacy literature, discussion with students, input from the Advisory Committee, and evaluation findings. Through these activities, the Investigators became convinced that mastery orientation could best be promoted by assisting students to successfully achieve goals they personally valued and by maximizing student self-attribution of success.

These principles became the guiding decision rules for component design and stimulated several component modifications. First, the originally proposed assessment of student capabilities and needs by others was redesigned to include student participation in the completion of the assessment and student selection of goals. In fact, the final version of the assessment appearing in the Student Guide is formatted as a self-assessment that the student may solicit help to complete. Second, traditional methodologies of "training "that emphasize trainer instruction in strategies only understood by the trainer, were replaced by coaching methodologies that emphasize providing information, support, and assistance under the guidance of the student. This was accomplished by articulating the general steps in strategies used to perform activities (i.e., problem-solving, planning, managing support, meeting friends, self-management, etc.) and instructing students in the application of those steps to their achievement of personal goals. The adoption of this approach required the development of student-directed materials that enabled students to self-teach the strategies as much as possible, and placed the instructor in the role of coach, assisting students to develop competence in the application of steps to their activity goals. This change necessitated a major shift in the perspectives of educators and therapists implementing the model. Instead of identifying student goals and working from a fixed curriculum to train, staff had to learn strategies to support, empower, and make their expertise available to the students. For example, staff learned that they should not automatically decide what help a student needs and give it. Rather, they should assist to student to define the help needed and communicate to the student that they are one resource he or she may want to call on. As is evident, this change in approach necessitated coaches learning to make decisions regarding how much information, support, and structure to provide. Much emphasis was placed on assisting coaches to shape their responses based on their determination of the level of support students needed to achieve success. In most cases, they were encouraged to make these determinations in partnership with the students.

### Development of Student-Directed Materials

As described above, the goal of the project shifted toward "giving away" to students much of the information, expertise, and power normally held by the adult "experts" who instruct them. The preparation of this material presented many obstacles, some of which remain to be solved. Foremost, the materials had to be prepared to maximize learning and generalization among students with various levels of physical and cognitive capabilities. As many of the strategies present cognitive complexity, much time was spent trying to figure out how to simplify them without making the material boring for students without severe cognitive challenges. Materials also had to be made "teenage friendly", presented in such a way as to maintain interest and motivation. Many strategies were field-tested, including presentation of the strategies in generic steps that could be applied across different activity goals students might select; presentation of steps on worksheets students could use independently of the rest of the written material; use of multiple exemplars of the application of strategies, cutting across different challenges and activity domains; use of audio tapes as a supplement or replacement to written materials; and provision of supplementary information from other sources to address additional learning needs students might have (e.g. basic social skills materials). These strategies proved beneficial, however the problem of designing materials to address various teenage interests continues to require attention. In response to this need, a consultant was hired in the final months of the project to begin another revision of the materials. This revision of materials was partially completed and is included in Appendix E. Further refinement of materials is underway through a second federally-funded project.

### Identifying Appropriate Strategies to Promote Student Coping with Disability.

The original objectives indicated that student support groups would be conducted to provide youth with opportunities to discuss disability-related challenges and solutions with one another. However, very early in the Project, students indicated that they did not want to meet in groups because they already had contact with one another and did not have time in their school schedules to meet. Additionally, the two members of our Advisory

Committee with Disabilities shared their perspective that the emphasis of the Project should be directed towards maximizing student competence and independence in inclusive school activities while also providing them with community-based opportunities to learn disability-related independence strategies. On-going discussion, in conjunction with a review of the independent living literature, resulted in a decision to demonstrate and evaluate the efficacy of mentoring experiences with adults as an alternative to school-based peer support groups. As is reflected in the evaluation of the mentoring component, this approach was well received by students and effectively promoted their disability-related knowledge and self-confidence. It is interesting to note, that the peer support conferences for youth and their mentors were well received as an element of mentoring, even though peer support in isolation was not preferred by youth.

Supporting Parents

The original objectives included the formation of a parent support group for the purpose of providing parents with opportunities to talk with one another and learn additional strategies to promote their sons and daughter's independence. Upon approaching parents with this idea, the Investigators discovered that most did not wish to meet in a group. Parents most often cited time and other logistical barriers to participation while also expressing that a group would have been more helpful when their children were younger. As a result, a parent group was replaced with bi-weekly phone-based parent coaching and 2-3 home visits per parent. Parents were also sent informational material about strategies to promote their children's mastery. Although most parents indicated that the material was helpful when they read it, many did not read it. To encourage parent involvement, brief summaries of key promotion themes were prepared and reviewed with parents and youth during home visits. Parents reported high levels of satisfaction and utility for this approach. The Investigators believe it represents an important supplement to mailing materials and providing phone-based support.

Critical Need for Skill in Support Management

Although an original objective of the proposed project, it became clear that management of support warranted intensive emphasis beyond that originally anticipated. Many students were not engaging in activities at optimal levels of independence because an overabundance of assistance was being provided. In addition, as indicated by evaluation results, many students did not understand their support routines, and thus, were unable to direct their helpers. This was the case even for those students without significant cognitive challenge. Much attention was directed to designing procedures for students to use to identify and direct assistance provided by others. Qualitative and quantitative evaluation of these strategies revealed that they were effective in promoting student direction of assistance and facilitated generalization of direction behaviors to additional helping routines. The Investigators are convinced that management of support is an essential skill for students to learn, and advocate for additional scientific and demonstration attention to this area.

### Number of School Districts Participating in the Project

Originally, the objectives indicated that the project would be implemented in three school districts. This number was reduced to two districts for two major reasons. First, the additional resources required to design and implement a student-directed model made involvement of a third district difficult. Second, the integration of a mentoring component within the model required the building of collaborative agreements and relationships between the Oregon Research Institute, school districts in each site, and independent living programs in each site. Much attention was directed to defining and promoting the relationship between the school districts and independent living centers. These relationships proved productive and we believe this approach constitutes an important innovation in building partnerships between schools and community agencies to serve students with disabilities.

## VII. EVALUATION STRATEGIES

The evaluation plan for the Mastery Project integrated qualitative and quantitative methodologies for the summative and formative evaluation of the model and project. The intention of the evaluation was to address stakeholder questions related to the impact of model components, demands of implementation, and overall utility of the model, utilizing validated interactive methodologies (Guba & Lincoln, 1989).

Single-subject methodologies were utilized to evaluate the impact of skill facilitation provided in Component One; one study investigated the impact of school-based instruction on functional independence in community settings; while the second study investigated the efficacy of our approach to promoting student management of support. The Mentor Component was evaluated through a small-scale randomized study that investigated the extent to which exposure to mentors increases the disability-related knowledge and self-efficacy of students and promotes the positive perceptions and expectations of their parents. Additional information regarding each of these studies is found in Appendix F. Detailed case studies were conducted to document and evaluate the overall impact of involvement in the model on youth and their parents. These studies are presented in this section.

## Case Descriptions

Table 3 presents a summary of the characteristics and goals of students who participated in Year 3 full model implementation. The following discussion describes the process and outcomes associated with the participation of each student in R.I.S.C..

### Dave

Dave was a 20 year old Caucasian male with severe cerebral palsy. He was unable to speak and used an E-TRAN Board to communicate. Dave had virtually no use of his limbs: he used a power chair controlled by head movements and required complete assistance to meet all of his personal needs. Dave was also labeled with below average cognitive abilities and received special educational services. During the course of his involvement in the Project Dave's programming included a work experience training and community-based instruction in life skills (e.g. shopping, riding the bus). Dave lived with his paternal grandparents in a modest home located in a rural area.

In conjunction with his participation in a functional assessment and instruction in goal-setting, Dave picked three major activity goals to pursue during the year. Dave's goals were to manage his daily helping routines, to learn about options for housing for people with disabilities, and to organize a team to support his goals.

Dave was also introduced to his mentor, an adult with severe cerebral palsy who lived independently. Dave performed many activities with his mentor: he participated in improvisational dance lessons, rode in the sidecar of his mentor's bike, went sailing, and stayed at his mentor's home overnight.

Following goal selection, Dave scheduled a planning meeting during which he presented his goals and enlisted support from his grandparents, school staff, and project staff. The meeting was attended by Dave's physical therapist, the Director of Transition services for his school district, his aide, his mentor, his grandparents, and his facilitator, a representative of the local independent living center. One immediate request Dave made of these participants was their attendance at monthly meetings to assist Dave to plan for future independence.

These meetings were initiated shortly thereafter and attended by up to 12 representatives of agencies serving adults with physical and multiple challenges, including the Disabled Services agency, Vocational Rehabilitation, a supported employment program, the Direction Service program, the Independent Living Program, and the Developmental Disabilities Program. Dave began as a relatively passive participant in these meetings, with his facilitator assuming major responsibility for directing the group. However, Dave received coaching prior to, and following each meeting. Coaching focused on assisting Dave to identify his long term goals, to debrief on the

Table 3. Mastery Project
Year 3 - Student Goals

| Student (AKA) | Age | Disability | Goals |
|---|---|---|---|
| Dave | 20 | Cerebral Palsy | 1. To organize an independent living team<br>2. Manage helping routines.<br>3. Investigate housing options |
| Tom | 15 | Cerebral Palsy | 1. Visit a friend's house<br>2. Make snacks for myself<br>3. Get my own school materials |
| Sara | 13 | Arthritis | 1. Go to an opera with a friend<br>2. Brush my teeth<br>3. Shop for my own clothes |
| Mike | 17 | Muscular Dystrophy | 1. Meet with faculty in Physics Department of the University<br>2. Communicate with others using a modem<br>3. Get a pen pal |
| Bill | 11 | Muscular Dystrophy | 1. Use my locker<br>2. Join a club at school<br>3. Clear the table after dinner |
| Mary | 13 | Cerebral Palsy | 1. Open the choir room door<br>2. Have lunch with a friend<br>3. Go to the mall with a friend<br>4. Manage school bathroom routine |
| Lisa | 20 | Cerebral Palsy<br>Frederick's Atoxia | 1. Bet in and out of my home<br>2. Become more independent on the bus.<br>3. Direct help I get in the community.<br>4. Drive my wheelchair in the community as independently as possible |
| Joan | 13 | Spinal Cord Injury | 1. Dress myself as independently as possible<br>2. Use the public bus system<br>3. Wash my hair as independently as possible<br>4. Transfer from my bed to chair<br>5. Turn the bedroom lights off and on |

BEST COPY AVAILABLE

outcomes of the preceding meeting, and to plan the following meeting. Dave's facilitator gradually faded her support and he assumed more responsibility for running the meetings. By the end of the year, Dave was openly telling the group of his goals and asking members to complete specific activities on his behalf.

Several outcomes were achieved through the efforts of Dave and his team. First, it was discovered that Dave's grandparents were receiving no funding for his care, support they were eligible for but had never requested. They made application for support and agreed to save the $400 they received each month to assist Dave to hire a personal assistant to help him at home and in the community. These funds enabled Dave to hire an aide to accompany him to recreational events in the city on weekends. Dave also established a plan for self-support that permitted him to save money to purchase a computer to perform graphics on a job the supported employment program was negotiating for him. Finally, Dave applied for both Section 8 housing and personal assistance services in preparation for independent living.

Dave devoted much of his project time to learning and applying strategies for management of support. In association with his review of written materials, Dave selected helping routines that he wanted to direct more actively. He focused on those routines completed between the time he arrived home from school and prepared for school in the morning. These routines included eating, dressing, grooming, and evening recreation.

Observations of each routine were conducted in Dave's home with his physical therapist present. Current steps for Dave to complete each routine with his grandparents were observed and recorded. Next, routines were revised to accommodate to Dave's preferences for assistance he would receive from a personal assistant. For example, Dave's grandmother typically cradled him in her arms to feed him and brush his teeth. Dave decided he would rather be fed and have his teeth brushed while sitting in his wheelchair. Additional methods were designed for Dave to communicate eating preferences and stop his helper. These methods were not necessary when Dave was being helped by his grandmother because she felt she was able to understand Dave's preferences without the necessity of communication with him. The major steps in each of Dave's routines were written down and photographed. This information was compiled into a management of support guide that Dave could show to helpers before they assisted him.

Following Dave's definition of his helping routines, an arrangement was made his school district for Dave to gain evening access to an apartment used for living skill training during the school day. Dave made a preliminary plan to spend several overnights with an aide at the apartment. Dave's school aide agreed to accompany him and to require Dave to give instructions for each of the routines he needed help to complete. Dave agreed that his aide would do exactly what he directed, no more or no less.

Dave's experiences during 8 overnights with his aide were generally positive. Dave became increasingly proficient at directing his support, although on one occasion he became frustrated that his aide did not automatically bring some supplies when they went to the mall. Following this incident, Dave indicated he wanted to discontinue his team meetings and was no longer interested in living on his own because it was "too much work". Dave's mentor and facilitator validated his frustration, while also reviewing the progress he had made and emphasizing the implications of disbanding his team. After some reflection, Dave decided that he wanted his team to continue assisting him and he would return to the apartment.

At the conclusion of his participation in R.I.S.C., Dave decided to maintain his support team and requested that they assist him to make arrangements to spend one weekend per month away from home with a personal assistant. During this period, Dave also wanted to begin working part-time. Dave's team was able to assist him to achieve these goals, and currently he has found an assistant and is looking for permanent housing.

Dave's grandmother reported that R.I.S.C. had helped Dave to become more self-sufficient:

> He used to say grandpa you make something for me and now he's trying to tell us, you know, that it should be done this way of that way.
>
> Well, he tells us, you know, that he doesn't want to do this or that, you know... and I'll say make up your mind, you know, you tell me, and like the other day he wanted to get up and he laid there, and he said I don't know. I said well, you got to make your mind up, I gotta know what. And so, we were talking and finally he said, I want to take the manual chair. I said okay, that's all we wanted to know. Now he makes decisions you know.

### Joan

Joan was a 13 year old Hispanic female with paraplegia secondary to a spinal cord injury. Joan attended 7th grade, demonstrated average cognitive ability, and lived with her mother. Joan participated in R.I.S.C. following surgery for spinal fusion. She wore a halo brace throughout her year in the project.

Joan's selection of goals was shaped by her desire to be as independent as possible while recuperating from surgery. Joan's mother experienced back problems and Joan was acutely aware of her mother's limitations in lifting her. Joan identified five specific goals: (a) be as independent as possible in dressing, (b) use the public bus, (c) wash her hair as independently as possible, (d) transfer from bed to chair as independently as possible, and (e) turn on and off the lights in her bedroom. Joan was also matched to a female mentor who experienced a spinal cord injury causing limitations similar to Joan's.

Home observations of Joan's dressing, hair washing, and transferring routines were conducted by Joan, her facilitator, and her mother. Specific steps and obstacles in each routine were identified and problem-solving strategies were discussed and trialed. Joan discovered that dressing posed two major barriers: sliding her clothes on and selecting clothes that would fit over her halo. Joan successfully ordered and used a reacher and a dressing stick to make easier sliding on her clothes. Additionally, her facilitator borrowed a halo brace similar to Joan's and accompanied Joan to the mall to pick out loose fitting clothes. Joan's facilitator wore her halo and tried on clothes for Joan to consider. Her facilitator also wore the halo throughout the mall on a dare from Joan. Joan was able to pick out clothing and she became less self-conscious of wearing her halo after this experience.

Joan and her facilitator rode the bus to and from the mall. They identified strategies that Joan could use to safely board the bus and pay the fare. Subsequently, Joan's mentor accompanied Joan on bus trips to provide her with practice in using her strategies. Her mentor also provided Joan with some practical strategies for dealing with strangers who might approach her in the community. Joan was able to maximize her independence in hair washing by designing a method to safely lean over her bed and wash her hair over a bucket held by her mother. She was also able to perform her own transfers with a standby assist provided by her mother. In each case, Joan also learned the steps she needed her mother to perform and practiced managing any assistance her mother provided. Finally, Joan purchased an inexpensive, commercially available environmental control device to enable her to control the lights in her room.

As Joan demonstrated success in achieving her goals, Joan's mother also exhibited increasing willingness to permit her to perform other activities such as cooking and going for walks in the community. Joan's mother reported that she felt new confidence in Joan's abilities once she saw that Joan had a logical, planful approach to use in accomplishing activities.

Joan also expressed satisfaction regarding her experience in the project, with the exception mentoring. Joan was unable to explain her discomfort with mentoring to her facilitator. However Joan's mother indicated that, although Joan indicated she liked her mentor and learned a lot through interacting with her, she felt uncomfortable because being with her mentor reminded her that she experienced a disability. Joan's facilitator also hypothesized her recent surgery may have exacerbated Joan's fears of life-long limitation. After the conclusion of the project, Joan expressed renewed interest in having a mentor.

### Mary

Mary was a 13 year old Caucasian female with severe cerebral palsy and mild cognitive delay; she had limited use of one hand, demonstrated a second grade reading level, and experienced much difficulty understanding abstract concepts. Mary attended a 7th grade classroom and lived with her mother, step-father, and three siblings.

Though R.I.S.C., Mary targeted three primary goals. She wanted to be able to open the choir room door at school, have lunch with a friend, and go to the mall with a friend. Mary also wanted to learn ways to more actively manage her school rest room routine. Observation of Mary attempting to open the choir room door revealed that she had difficulty grasping the door and backing up her chair in the narrow hallway to open the door. Mary applied the problem-solving strategies to identify two solutions to these barriers. First, she selected and ordered a rubber grip to place on the door knob. Second, she planned and conducted several practice sessions to learn how to navigate the hallway while holding the door. Mary and her facilitator mapped out highly specific methods for Mary to grasp the door, pull on the door while backing up, and move forward once the door was opened sufficiently. As Mary became proficient at these methods, she no longer required the rubber grip.

Like many students involved in the project, Mary found her second goal, having lunch with a friend, complicated to achieve. During the course of problem-solving strategies Mary might use to accomplish this goal, it became clear that Mary defined "a friend" as one particular student who was unavailable during lunch. Additionally, Mary acknowledged that she had never initiated even a "hello" to another student and felt very intimidated about talking with others. Through discussion, Mary and her facilitator decided to breakdown her goal into some more minor interaction steps that she could work toward in preparation for eating lunch with someone. Mary began by practicing saying "hello" to other students in the hall. She then expanded her interaction to initiating a brief conversation. Finally, in conjunction with a choir field trip, Mary arranged to eat lunch with a group of other students. In selecting students to approach, Mary was encouraged to begin with students who she liked and appeared to need friends rather than focusing on the most popular students at school. By the end of the school year, Mary had eaten lunch on several occasions with students from her choir class.

During the Spring, Mary problem-solved and carefully planned going shopping with a neighborhood friend at the mall. Mary asked her friend to go, arranged for transportation with her mother, and saved money for the trip. Mary's facilitator helped her conduct one "practice" visit to the mall during which they problem-solved strategies Mary could use to drive her wheel chair, pay for items, and eat a snack. Mary successfully completed this goal and visited the mall subsequently.

Mary's bathroom routine had been exclusively designed by her physical therapist with little input from Mary. As in the case of helping routines designed for many students with physical challenges, Mary's routine emphasized expediency over maximizing her participation. During a demonstration of her routine, Mary indicated that she wanted to both perform more steps independently and direct the form of help she received from her assistant. Mary, her facilitator, and her assistant decided that Mary could turn on the light, close the stall door, flush the commode, and wipe herself independently without requiring an inordinate amount of time. Mary also learned the precise steps she needed her assistant to perform and she practiced strategies for stopping and redirecting her routine if she was assisted incorrectly.

Throughout the year, Mary also participated in activities with her mentor. Mary's mentor was a married woman with cerebral palsy. They went to the mall on several occasions, they practiced driving their wheelchairs in the community and reviewed safety strategies, and Mary and her mother visited her mentor's home. Through this experience, Mary became more vocal about her ability to get married when she was older and her mother expressed increased confidence in Mary's safety in the community.

Mary also actively self-advocated with the staff who managed her swimming program. Mary didn't like swimming because she had to wait too long to get her bus and she preferred to swim in inclusive classes. As a result of her passive protest, Mary had developed a reputation among the staff as "lazy" and they resisted making any changes to accommodate her. To address this problem, Mary requested that her facilitator help her write a letter that described her problems and potential solutions. Mary then requested a meeting with the pool staff during which she read her letter aloud. Mary requested an opportunity to swim with nondisabled peers, permission to wait for her bus in a more comfortable location than the shower room, and some input into her swimming routine. Mary's requests were well received and the staff agreed to make some changes to accommodate her.

Mary and her mother reported high levels of satisfaction with the project. Her mother indicated that she enjoyed the parent readings and family meetings with Mary's facilitator. She felt that Mary's facilitator was able to provide personal attention to her needs that other staff had not provided. She also indicated that she felt encouraged because Mary had learned some specific strategies that she could apply to increase her independence. During her final interview, Mary's mother reported:

> Um, as far as the project, I think it was really good because it, uh, directed some of her energy into another way to look at things; instead of being so caught up on being negative, she had a lot of positive. Um, she got to do a lot of things with the mentor, and got to see another side to somebody else with a disability and how they dealt with things.
>
> It taught her a lot more....Like the school meetings. Taking charge of the talking, calling a meeting herself, you know setting the agenda, setting, you know, people there that she wanted, that were gonna participate with her. Um... telling them her goals and following through with them.

Lisa

Lisa was a 20 year old Caucasian female with cerebral palsy secondary to a traumatic brain injury. During high school, Lisa had also been diagnosed with a degenerative condition similar to Frederick's Ataxia. Lisa used a power scooter and experienced tremor and impairment in her vision, speech, and hearing. She also experienced mental retardation. Lisa lived with her aunt and uncle and attended a self-contained life skills classroom at a local community college. Lisa consistently presented herself as incapable of doing most activities and her aunt reported that she felt Lisa did not apply herself.

Lisa selected three major goals for her involvement in R.I.S.C.. She wanted to independently enter and exit her home, ride the bus as independently as possible, and drive her wheelchair in the community. Additionally, Lisa expressed interest in learning to direct people who accompanied her in the community.

Lisa was matched to a female mentor who also experienced cerebral palsy and cognitive challenges. Lisa's mentor lived independently in a supervised apartment and she and Lisa did a variety of activities including going shopping, bowling, riding the bus, and cooking dinner.

To identify strategies to enter and exit her home, Lisa and her facilitator arranged to observe her at home. During the observation Lisa's facilitator methodically assisted Lisa to identify each step she had to perform and associated barriers to independence. Lisa was unable to keep her chair on the ramp, she could not reach the doorknob from the ramp, and she could not pull open the door. Once in the doorway, Lisa also had difficulty navigating her chair through the crowded kitchen. After considering several options, Lisa and her facilitator concluded that she needed a new ramp with side guards and a level platform near the door. They also decided that Lisa would be most independent if she were provided with a power door that she could operate with a button on the inside and an adapted key on the outside. Finally, they decided that Lisa's mobility would be enhanced if her aunt and uncle would agree to move the kitchen table away from the door.

Lisa was very excited at the prospect of getting in and out of her home, however her aunt and uncle expressed reservation about the success of her plan. Lisa was reluctant to assert her wishes with her family and requested her facilitator's help. Lisa's facilitator was able to obtain her aunt and uncle's permission to complete and evaluate the effectiveness of one adaptation at a time, beginning with a new ramp.

A new ramp was constructed by volunteers from the local senior center. Following several trials of practice and the addition of a few red flags to the railing, Lisa demonstrated that she could use the ramp safely. Her aunt then consented to installing a power door and agreed to move the kitchen table if the new door enabled Lisa to enter and exit the house. A power door was purchased wholesale and installed at no cost by a contractor supportive of the project. Lisa was then able to exit and enter her home independently and the kitchen table was moved to facilitate her mobility.

Lisa enhanced her independence in the community by practicing taking the bus, driving her chair, and managing her assistants. In each case, Lisa was assisted to identify specifically what she needed to do and any assistance she needed from her helper. Lisa was quite perceptive in isolating her requirements for help. She determined that she needed her helper to walk one step behind her, walk on her right side, and avoid talking to her when Lisa was operating her chair. Lisa's application of these strategies improved her driving accuracy and resulted in Lisa requiring less assistance.

In conjunction with her first bus trip, Lisa was yelled at by the driver who complained she moved too slowly. Lisa's initial reaction was to cry and insist that she couldn't get on the bus by herself. Lisa's facilitator worked intensively with her to provide reassurance regarding her capabilities and to encourage her perseverance. Lisa agreed to attempt boarding the bus once again and received a positive response from the bus driver. Subsequently, she expressed anger at the first driver for not "giving her a chance".

During her participation in R.I.S.C., Lisa asked her facilitator to help her figure out how to go bowling with her boyfriend. Lisa, her facilitator, and her mentor went bowling on two occasions to problem-solve strategies to promote Lisa's participation. Lisa learned how to bowl with a ramp, to call a taxi to independently travel to and from the bowling alley, and to make arrangements with assistants to be on call to provide her with help in the bathroom. Lisa was able to independently go bowling on two occasions prior to the conclusion of the project.

Although Lisa's aunt and uncle maintained their reservations regarding Lisa's motivation, they reported that the project was useful in encouraging her. Additionally, shortly after Lisa began to enter and exit her home independently, her aunt accepted a full-time job. Lisa's evaluation of the project was very positive. She most enjoyed learning to take a taxi because she could do it with no help. She also reported that she felt safer driving her wheel chair in the community and was no longer afraid of taking the bus.

### Bill

Bill was an 11 year old African American student in 6th grade who experienced muscular dystrophy. Bill lived with his mother in a small apartment and he attended a junior high school several miles from his home. Prior to joining the project, Bill had broken his leg and began permanently using a wheelchair. His mother indicated that Bill was in rapid physical decline and she was becoming increasingly reluctant to permit him to do activities independently.

Bill's R.I.S.C. facilitator was an occupational therapist employed by the school district. Bill selected three activity goals on which to focus during the year: using his locker more independently, joining a club at school, and clearing the dining table after dinner. Bill also participated in several community-based activities with his mentor, a social worker from a local rehabilitation program who experienced a spinal cord injury.

Through observation and application of problem-solving strategies, Bill identified several obstacles to his locker use including his inability to reach the high shelf and clothes hook in the locker, difficulty remembering the combination to his lock, and conflict with his locker partner who often threw Bill's materials on the floor. To overcome these obstacles, Bill and his facilitator purchased and installed at proper heights, a sliding shelf for his locker and a clothes hook. Bill also obtained a small laminated wallet card that listed the combination to his locker. Finally, he arranged a meeting with the locker manager and described the problems he was having with his partner. Following their discussion, Bill was assigned another locker partner.

To achieve his second goal, Bill first gathered information about clubs active at school during the day. As Bill enjoyed chess and there was a chess club that met during lunch, he decided to investigate the possibility of attending. Bill and his facilitator met with the adult supervisor of the club and explained his interests. Bill then observed a club meeting and decided to join. Bill's major challenges to clearing the table involved difficulty carrying items and navigating his wheelchair. Following a home observation and discussion with his mother, Bill requested that she shift some furniture to make more room and he ordered a lap tray to hold the dishes. Mastering this activity required intensive practice because there was little room for Bill's wheelchair in the kitchen. Bill practiced regularly and reported his progress to his facilitator. His facilitator was also updated on Bill's progress during the course of bi-weekly phone contacts with Bill's mother.

Although Bill's mother was very supportive of his self-selected goals, she also wanted assistance to encourage Bill to sleep in his own bed at night. Through discussion with Bill, it became evident that he preferred to sleep in his mother's bed because she could turn him and he could wake her up if he needed help. Bill was willing to sleep in his bed if these problems could be overcome. Bill's facilitator assisted him to purchase an intercom to ensure that he could communicate with his mother during the night. She also assisted Bill to install some straps on his bed that he could pull to turn himself during the night. After these accommodations were provided, Bill began sleeping in his own bed.

During the project, Bill also independently applied the problem-solving steps to design a method for getting in and out of his bathtub. Bill's mother reported that he learned to use the commode as an intermediate transfer point in his movement in and out of the tub.

Bill performed several activities with his mentor. They went to the movies, performed grocery shopping, prepared and ate dinner, frequented the video parlor. Bill was particularly enamored with his mentor's van and expressed much interest in having his own transportation some day.

Bill and his mother expressed high satisfaction regarding his participation in the project. Bill reported that he "had a good time" and became less dependent on his mother's help. Bill's mother indicated that the project enhanced Bill's confidence and decreased her concern about Bill's independence because it provided Bill with a consistent approach that he could use to safely address barriers. As expressed by mother:

> Just his everyday, the way he does things, you know. It's the self-confidence, the "I know I can do it". And that's the R.I.S.C. project, that's what it's done. I mean, he was like I said, he was dependent on me for a lot. And I guess he found out, that a lot of the stuff he had me doing he could do himself. And that's what the program's all about.

### Tom

Tom was a 15 year old Caucasian male who experienced cerebral palsy. Tom primarily used a power wheelchair, however he could walk short distances with a walker. Tom also experienced limited use of his arms and hands that precluded his performance of find motor tasks. Tom was a freshman in high school and lived with his parents and one older sibling.

Tom was matched to a male mentor who experienced paraplegia and directed the local office of emergency services. His mentor was also married and active in a number of sports and community organizations. Although their busy schedules precluded Tom and his mentor from spending extensive time together, Tom did visit his mentor's home, and they went to a ball game and to a restaurant for dinner. Tom and his mentor also attended two peer support conferences with other youth and mentors involved in the project.

Tom's personal goals included visiting a friends house, making a snack for himself, and accessing his school materials. Tom also expressed a desire to more actively direct his school aide in taking notes for him. In the process of problem-solving strategies to achieve his first goal, Tom realized that he would need to interact with a potential friend before s/he would invite Tom to his or her home. As a result, Tom began by planning strategies to invite a friend to his house. He identified three potential students at school to invite, planned an evening of snacks and computer games, and obtained his parent's permission. The first two students he asked were busy, however the third agreed to come. The visit went well and both boys discovered a mutual interest in a particular computer game. Tom was approached by his new friend the following day at school and asked if he wanted to join a computer club with 6 other boys. Tom agreed and was invited to his friend's home the following weekend. To prepare for this visit, Tom contacted his friend and inquired about the accessibility of his home and bathroom. With support from the facilitator, Tom and his friend worked out a plan whereby his friend would help Tom get into the bathroom, if required. Tom's visit to his friend's home was a success and he became active in the computer club.

Tom was previously unable to make a snack for himself because the kitchen was not accessible to him. As a result, the focus of Tom's problem-solving was on identifying strategies to get down the 6 stairs leading to his kitchen. Tom was able to scoot down the stairs on his seat, however he could not get up off the floor without assistance and he could not walk about the kitchen. Following consultation between Tom, the facilitator, and Tom's physical therapist, it was decided that Tom could crawl down the stairs and pull himself up on a chair. Once standing, Tom could use a walker to move about the kitchen. Tom was permitted to bring his walker home from school and a chair was placed in the kitchen. After several trials of practice, Tom was able to successfully negotiate the stairs and get up from the floor. To promote his access to food and supplies, Tom negotiated an arrangement with his mother to leave specific snack items in lower cupboards and to place the milk in a lower door shelf of the refrigerator. These accommodations permitted Tom to begin making a snack for himself each afternoon after arriving home from school.

Tom's final targeted goal was to access his school materials. Tom stored his books and papers in a nap sack hooked to the back of his chair. However, he was unable to reach these materials without assistance. While in the process of problem-solving this activity, Tom and his facilitator attended a technology exposition and Tom learned that someone had a container constructed for a wheelchair that would swing to the side and provide the user with easy access to materials. Tom learned that this device was custom made and he decided to try to identify someone in the community who could construct it. Following several phone calls and a visit by Tom to meet another person with such a container, a technician was located. At the conclusion of the school year, Tom was awaiting the completion of his container.

In conjunction with his review of steps for managing support, Tom identified specific procedures he wanted his note takers to follow. These procedures included writing notes on alternate lines of his pad, numbering the pages, and following his cue for recording information. Tom reviewed these procedures with his assistant and provided feedback regarding his assistant's accuracy in following the procedures.

With assistance provided by his facilitator, Tom also applied to participate in an international exchange program among people with disabilities. He was accepted and spent the following summer in Mexico. Tom and his mother expressed high levels of satisfaction regarding his involvement in R.I.S.C.. Tom expressed particular pleasure about meeting a group of friends and learning that he could figure out how to become more independent. His mother was most pleased with the contacts the project had fostered between her son and successful adults with disabilities.

### Sara

Sara was a 13 year old Caucasian female with severe musculoskeletal anomalies. She used a power wheel chair and had limited use of her shortened arms and deformed hands. Sara was in 9th grade and lived with her mother and younger brother.

Sara was matched to a female mentor who was a playwright and former college counselor. They participated in a number of independent activities in the community including visiting the community college, attending a play, recording a song at a record studio, and shopping at the mall. They also attended a series of conferences with the other students and mentors in the project. These conferences focused on self-advocacy, independent living, community resources and managing help.

Sara's targeted goals were to: (a) go to the opera with a friend, (b) brush her teeth independently, and (c) shop for clothing. Sara applied the problem-solving steps to identifying barriers and solutions to going to the opera with a friend. She discovered that the following steps would be difficult: purchasing the tickets (she couldn't reach the counter or handle the money); getting dressed for the event ; pushing buttons on the elevator; and carrying her food. To address these barriers Sara planned to ask the ticket taker to remove her money from her pouch and place the tickets in her mouth; ask her mother to assist her with dressing; use her mouth stick to push the elevator button; and ask her friend or the counter person to carry her food to a table.

Sara integrated her problem-solving strategies into a comprehensive plan for going to the opera. She then asked a friend to accompany her, called the performing arts center to reserve tickets, and arranged with her mother assistance in dressing. Sara's facilitator rehearsed with Sara a script for her phone call and helped Sara identify and practice some conversational strategies to use with her friend. Sara was able to successfully use her strategies to have an enjoyable time at the opera. She also generalized her application of these opera strategies to successfully go to a movie and the museum with two additional friends.

Sara was also able to identify effective strategies for brushing her teeth. She and her facilitator conducted an observation of her brushing and identified three major obstacles: turning on the tap, putting toothpaste on her brush, and holding the brush. Together they identified and ordered three inexpensive adaptations to overcome these barriers. Sara obtained a "tap turner", "tube squeezer", and a "gooseneck" to hold her brush.

Sara's final targeted goal, to go clothes shopping, was completed with support provided by her mentor. Sara and her facilitator problem-solved Sara's challenges to shopping following her first attempt with her mentor. Sara's primary barriers to shopping were navigating around the clothes racks, removing the clothes from the rack, and trying the clothes on. To address these obstacles, Sara approached the sales manager in her favorite store and explained her challenges. The manager agreed to move some of the clothing racks to provide Sara access. Additionally, the manager indicated that she would be willing to assist Sara to remove the clothes from the racks. When Sara explained her difficulty in trying clothes on in the store, the manager indicated she would assist Sara to try on some clothing and Sara was free to purchase other clothing and try it on at home. Following her discussion with the sales manager, Sara frequented the store on two occasions with her mentor and obtained assistance from the sales staff. In association with shopping, Sara also reviewed and practiced with her facilitator steps for managing help provided by the sales staff.

During the course of her involvement in R.I.S.C., Sara also joined a poetry club, wrote an article for the school newspaper, attended a protest march, and won an award for her poetry. Sara's mom participated in bi-weekly phone contacts with her facilitator, however she indicated she was unavailable for family meetings and preferred that project staff focus their attention on Sara. Both Sara and her mother reported that the project was very useful in assisting Sara to assimilate to her new school and to begin to visualize her future potential as an adult.

### Mike

Mike was a 16 year old Caucasian male with advanced muscular dystrophy. He was a senior in high school and lived with his parents and two siblings. Considered "gifted" intellectually, Mike used a power wheelchair and had virtually no use of his arms and hands. Prior to becoming involved in R.I.S.C., Mike had experienced rapid physical decline and was no longer able to tolerate sitting in his wheelchair more than a few hours per day. As a result, Mike's school day was shortened and he was required to spend each afternoon and evening in bed. Despite these problems, Mike was determined to graduate from high school and both he and his parents felt his participation in R.I.S.C. would provide him with an opportunity to focus on his capabilities.

Mike identified three major goals: meet with a faculty in the physics department at the university; communicate with others using a modem; and get a pen pal. To achieve his first goal, Mike, with coaching from his facilitator, called the physics department to find out with which faculty member he could meet. Mike then scheduled a meeting and prepared a list of questions to ask. Mike requested that his facilitator accompany him on the appointment for "moral support". They identified methods the facilitator could use to assist Mike and reviewed the steps Mike would apply to manage his facilitator's help. Mike also asked his mother to drop him off and pick him up from the meeting. Mike successfully used these strategies to attend the meeting.

Although Mike had a computer, he had never used a modem. Mike and his facilitator problem-solved strategies Mike could use to access, install, and use a modem. His facilitator provided Mike with the name of a colleague who used his modem to participate in several bulletin boards. This person offered to give Mike his spare modem and provided Mike with installation instructions. Mike then negotiated the installation of his modem with his father. After the modem was installed, Mike used it to communicate with the facilitator's colleague and he regularly participated in a number of bulletin boards through which he obtained additional information on jobs in physics. Mike also ordered a head stick to facilitate his use of his computer.

Mike's final targeted goal was to get a pen pal in Germany. Mike spoke fluent German and aspired to find a German pen pal for a number of years. To accomplish this goal, Mike asked both his German teacher and a faculty member at the university for information about pen pal programs. Mike's facilitator assisted him to articulate his questions and rehearse his conversations with these contacts. Mike was provided with a list of possible pen pals and he prepared a letter to send to each. Once again, Mike's facilitator assisted him to design the letter. Mike then mailed the letters and was awaiting a reply as the project concluded.

During Mike's involvement in R.I.S.C., his family moved into a new home. Mike was anxious to assist his family with their move and requested that his facilitator help him figure out ways he might be able to contribute. They identified a number of ways Mike might help and, following a conversation with his mother, Mike decided to complete all their change of address cards and to help his parents identify strategies Mike could use to leave the house in an emergency.

Although Mike's health was precarious during his participation in the project, he reported that achieving his goals made him feel like his life was worthwhile. Mike's parents also shared that his involvement helped them realize that Mike maintained his zest for activity and that their support of his goals was important.

## Demands of the Model

Demonstration of R.I.S.C. by local staff indicated that full-model implementation requires an average of 2 hours of educational facilitator and 1 hour of independent living staff time per week per student. From a school perspective, this time commitment is comparable to that currently provided by related service staff to students with physical and multiple disabilities. As such, it does not require time commitments perceived as atypical in most school systems. We also learned that monthly coordination between school and independent living staff is essential for smooth model implementation. Ideally, such coordination should be conducted during team meetings attended by all staff involved in model delivery. Finally, we have determined that bi-weekly team meetings are essential during the first six months of implementation by staff who are new to the model. The up front investment of technical assistance and meeting time facilitates staff acquisition and implementation of RISC values and procedures and promotes maintenance of instructional fidelity. This is considered essential to staff acceptance and integration of student-directed approaches in their work; an approach very foreign to most educational staff who serve students with physical and multiple disabilities.

## Summary

Experimental findings, satisfaction and utility reports, and case descriptions suggest that the R.I.S.C. Model was both effective and perceived as useful and feasible to implement. This model appears to constitute a comprehensive approach to promoting the independence and mastery orientation of youth with physical and multiple disabilities. R.I.S.C. appears to be particularly well-suited to middle school aged adolescents because it facilitates independence shifts typically undertaken by adolescents and in that age group. A formal controlled field-test of R.I.S.C. is essential to provide additional validation for the model.

# VIII. PROJECT IMPACT

## Dissemination.

The activities and outcomes of the project were disseminated through a series of national and regional presentations. The project was presented at TASH during each of the three demonstration years. R.I.S.C. was also presented at two annual meetings of the Therapists in Education Conference attended by over 200 therapists in Oregon. Finally, the Investigators were invited to present the model to the Annual Meeting of the Ohio Developmental Disabilities Council.

Project manuscripts included in the Appendices are currently being prepared for submission for publication. Additionally, the case descriptions provided in the Evaluation Section of this report are being integrated into a project descriptor paper that will be submitted to a refereed journal. Paul H. Brookes Publishing has also indicated interest in publishing an edited volume based on the model and project. The Investigators are currently awaiting a letter of commitment from the publisher. Although Brookes Publishing has also expressed an interest in disseminating the student, facilitator, and parent guides, the Investigator's have decided to defer publication of these materials until final revisions are completed within the coming year.

## Continued Implementation of R.I.S.C.

Impressed by the impact of RISC on students, parents, and staff, Portland Public School District and Access Oregon, the local Independent Living Program, have decided to integrate the model into their existing services. Staff who were intensively trained in the application of the model are now initiating an inservice and technical assistance program that will result in their preparing approximately 20 additional staff to implement RISC with middle school and high school students who experience physical and multiple disabilities. R.I.S.C. is also being disseminated to school districts in New Hampshire through a three-year federally funded outreach project

(PR# H086U20006), and the model is being formally field-tested through a federally funded self-determination model demonstration project (PR#158K20006).

## IX. FURTHER INFORMATION AND ASSURANCES

The final report on the Mastery Project has been sent to ERIC and the title page and abstract have been forwarded to those sources required by OSERS. Further information regarding the model and project can be obtained by contacting the Principal Investigators.

# X. REFERENCES

ARC of the United States Self-Advocacy Committee. (1989). Building self-advocacy in the community: A model workshop to begin a self-advocacy group. Arlington, TX: Association for Retarded Citizens of the United States.

Agran, M., Martin, J. E., Mithaug, D. E. (1989, Winter). Achieving transition. Teaching Exceptional Children, pp. 4-7.

Albin, R.W., Horner, R.H., Koegel, R.L., & Dunlap, G (Eds.). (1987). Extending competent performance: Applied research on generalization and maintenance. Eugene, OR: University of Oregon.

Allsop, J. (1980). Mainstreaming physically handicapped students. Journal of Research and Development in Education, 13(4), 37-44.

Anderson, J., & Goetz, L. (1983, November). Social interactions between severely handicapped students and their peers: A preliminary report. Paper presented at the annual meeting of The Association for the Severely Handicapped, San Francisco, CA.

Anthony, W. A. (1972). Societal rehabilitation: Changing society's attitudes toward the physically and mentally disabled. Rehabilitation Psychology, 19, 117-126.

Bailey, D.B. (1989). Issues and directions in preparing professionals to work with young handicapped children and their families. In J. Gallagher, P. Trohanis, & R. Clifford (eds.), Policy implementation & PL 99-457: Planning for young children with special needs. Baltimore: Paul H. Brookes Publishing.

Balcazar, F.E., Seekins, T., Fawcett, S.B. & Hopkins, B.L. Empowering people with physical disabilities through advocacy skills training. (1990). American Journal of Community Psychology. 18(2) 281- 296.

Bandura, A. (Ed). (1971). Psychological modeling: Conflicting theories. Chicago: Aldine-Atherton.

Bandura, A. (1986). Social foundation of thought and action: A social cognitive theory. New York, NY: Prentice-Hall.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavior change. Psychological Review, 84, 191-215.

Barrera, M., & Garrison-Jones, C. V. (1988). Properties of the Beck Depression Inventory as a screening instrument for adolescent depression. Journal of Abnormal Child Psychology, 16(3), 263-273.

Baumgart, D., Brown, L., Pumpian, I., Nisbet, J., Ford, A., Sweet, M., Messina, R., & Schroeder, J. (1982). Principle of partial participation and individualized adaptations. Journal of the Association for Persons with Severe Handicaps, 7(2), 17-22.

Baumgart, D., & Van Walleghem, J. (1986). Staffing strategies for implementing community-based instruction. Journal of the Association for Persons with Severe Handicaps, 11(2), 92-102.

Bednar, R. L., Wells, M. G., & Peterson, S. R. (1989). Self-esteem: Paradoxes and innovations in clinical theory and practice. Washington, D.C.: APA.

Bellamy, G. T., Horner, R. H., & Inman, D. P. (1979). Vocational habilitation of severely retarded adults. Baltimore, MD: University Park Press.

Bellamy, G., Horner, R., & Boles, S. (1980). Multiple evaluation of a model habilitation and education program for severely handicapped adults. Final Report. Grant No. G00760-5455. Eugene, OR: University of Oregon Center on Human Development, Specialized Training Program.

Bernard, H. W. (1971). Adolescent development. Scranton, PA: Intext Educational.

Blanchard-Fields, F., & Irion, J. C. (1988). Coping strategy from the perspective of 2 developmental markers: Age & social reasons. Journal of Genetic Psychology, 1988, 149(2), 141-151.

Bradley, R. H., & Caldwell, B. M. (1979). Home observation for measurement of the environment: A revision of the preschool scale. American Journal of Mental Deficiency, 84, 235-244.

Bricker, D. D. (1978). A rationale for the integration of handicapped preschool children. In M. J. Guralnick (Ed.). Early intervention and the integrating of handicapped and nonhandicapped children, (pp. 3-26). Baltimore, MD: University Press.

Brigham, T. A. (1989a). Self-management for adolescents: A skills training program. New York: Guilford Press.

Brigham, T. A. (1989b). Managing everyday problems. New York: Guilford Press.

Brinker, R. P. & Thorpe, M. E. (1986). Features of integrated educational ecologies that predict social behavior among severely mentally retarded and nonretarded students. American Journal of Mental Deficiency, 91(2), 150-159.

Brinker, R.P. & Thorpe, M.E. Integration of Severely Handicapped Students and the Proportion of IEP Objectives Achieved. (1984) Exceptional Children. 51(2) pp. 168-175

Brodsky, M., & Wilson, D. (1989). On the agenda: Oregon's chronically ill children and their families. Salem, OR: Oregon Department of Education.

Brooks, N.A. Self-empowerment among adults with severe physical disability: A case study. (1991). Journal of Sociology & Social Welfare. 18(1), 105-120.

Brophy, J., & Good, T. (1974). Teacher-student relationships: Causes and consequences. New York: Holt, Rinehart & Winston.

Brotherson, M. J., Backus. L. H., Summers, J. A., & Turnbull, A. P. (1986). Transition to adulthood. In J. A. Summers (Ed.), The Right to Grow Up: An Introduction to Adults with Developmental Disabilities, (pp. 17-44). Baltimore, MD: Paul H. Brookes.

Brotherson, M. J., Houghton, J., Turnbull, A. P., Bronicki, G. J., Roeder-Gordon, C., Summers, J. A., & Turnbull, H. R. (1988, September). Transition into adulthood: Parental planning for sons and daughters with disabilities. Education and Training in Mental Retardation, pp. 165-174.

Brown, L., Branston, M. B., Hamre-Nietupski, S., Pumpian, I., Certo, N., & Gruenwald, L. (1979). A strategy for developing chronological age appropriate and functional curricular content for severely handicapped adolescents and young adults. Journal of Special Education, 13(1), 81-90.

Brown, L., Nietupski, J., & Hamre-Nietupski, S. (1976). The criterion of ultimate functioning and public school services for severely handicapped students. In M. A. Thomas (Ed.). Hey, don't forget about me: Education's investment in the severely, profoundly, and multiply handicapped, pp. 197-209). Reston, VA: Council for Exceptional Children.

Brown, L., Pumpian, I., Baumgart, D., Vandeventer, P., Ford, A., Nisbet, J., Schroeder, J., & Gruenewald, L. (1981, May). Longitudinal transition plans n programs for severely handicapped students. Exceptional Children, 624-630.

Brown, R.I. & Hughson, E.A. Towards a model of rehabilitation. (1989, Jan). International Journal for the Advancement of Counselling. 12(1), 29 - 38.

Browning, P., & Foss, G. (1977). Training Evaluation Kit. Eugene, OR: Research and Training Center in Mental Retardation. Unpublished manuscript, University of Oregon.

Campbell, P. H. (1989). Students with physical disabilities. In R. Gaylord-Ross (Ed.), Integration Strategies for Students with Handicaps, (pp. 53-76). Baltimore, MD: Paul H. Brookes.

Clark, F. A., Mack, W., & Pennington, V. (1988). Transition needs assessment of severely disabled high school students and their parents and teachers. The Occupational Therapy Journal of Research, 8(6), 323-344.

Clark, R. M. (1980). Family life and school achievement: Why poor black children succeed or fail. Chicago, IL: University of Chicago Press.

Corcoran, K., & Fischer, J. (1987). Measures for Clinical Practice: A Sourcebook. New York, NY: Macmillian Free Press.

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 98(2), 310-357.

Cole, J. A. (1983). Skills training. In N. M. Crewe & K. Z. Irving (Eds.), Independent Living for Physically Disabled People, (pp. 187-204). San Francisco: Jossey-Bass.

Comegys, A. (1989). Integration strategies for parents of students with handicaps. In R. Gaylord-Ross (Ed.), Integration Strategies for Students with Handicaps, (pp. 339-350).

Converse, H. D., & Thompson, J. B. (1989). Timbers assessment of concepts of independent living. In S. C. Hey & D. Evans (Eds.), The changing world of impaired and disabled people in society. Salem, OR: Society for Disability Studies and Willamette University.

Cooley, E. (1989). Community Support: The role of volunteers and voluntary associations. In G. H. S. Singer , & Irvin, L. (Eds.) Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Coopersmith, S. (1967). The antecedents of self-esteem. San Francisco, CA: W. H. Freeman and Co.

Corcoran, K., & Fischer, J. (1987). Measures for clinical practice: A source book. New York: The Free Press.

Cottone, R. R., Handelsman, M. M., & Walters, N. (1985, Summer) Understanding the influence of family systems on the rehabilitation process. Journal of Applied Rehabilitation Counseling, 2, 37-40.

Crewe, N. M., & Irving, K. Z. (1983). Independent living for physically disabled people. San Francisco: Jossey-Bass.

Crewe, N. M. (1983). Freedom for disabled people: The right to choose. In N. M. Crewe, & K. Z. Irving (Eds.), Independent Living for Disabled People, (pp. 357-361). San Francisco: Jossey-Bass.

Cruikshank, W. M. (Ed.). (1976). Cerebral palsy: A developmental disability. Syracuse, NY: Syracuse University Press.

Daniels, D., Moos, R.H., Billings, A.G., & Miller, J.J. (1987). Psychosocial risk and resistance factors among children with chronic illness, healthy siblings, and healthy controls. Journal of Abnormal Child Psychology, 15 (2), pp. 295 - 308.

Darling, R. B. (1983). Parent-professional interaction: The roots of misunderstanding. In M. Seligman (Ed.). (1983). The family with a handicapped child - understanding and treatment, (pp. 95-36). New York: Gruhne and Stratton.

Davies, R. R., & Rogers, E. S. (1985). Social skills training with persons who are mentally retarded. Mental Retardation, 23(4), 186-196.

Davis, S. E., Anderson, C., Linkowski, D. C., Berger, K., & Feinstein, C. F. (1985). Developmental tasks and transitions of adolescents with chronic illnesses and disabilities. Rehabilitation Counseling Bulletin, 29(2), 69-80.

Deffenbacher, J. L., & Guinn, R. M. (1982). The self-control of anxiety. In P. Karoly & F. H. Kanfer (Eds.). Self-management and behavior change. New York: Pergamon.

DeJong, G. (1979). The movement for independent living: Origins, ideology, and implications for disability research. Ann Arbor, MI: University Centers for International Rehabilitation.

DeJong, G., & Wenker, T. (1983). Attendant care. In N. M. Crewe & K. Z. Irving (Eds.), Independent Living for Physically Disabled People, (pp. 157-170). San Francisco: Jossey-Bass.

de Vries, H., Dijkstra, M., & Kuhlman,, P. (1988). Self-efficacy: The third factor besides attitude and subjective norm as a predictor of behavioral intentions. Health Education Research, 3(3), 273-282.

Des Jardins, C. (1986). Assertiveness is/is not. In F. Weiner (Ed.), No apologies: A guide to living with a disability, written by the real authorities -- people with disabilities, their families and friends (pp. 122-123). New York: St. Martin's Press.

Dolce, J.J. (1987). Self-efficacy and disability beliefs in behavioral treatment of pain. Special Issue: Chronic pain. Behaviour Research & Therapy. 25(4), 289 - 299.

Donovan, A. M. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. American Journal on Mental Retardation, 92(6), 502-509.

Dudley, G. D. M. (1980). A behavioral assessment of an assertiveness training program for parents. Dissertation Abstracts International, 41(4).

Dunn, M. E. (1975). Psychological intervention in a spinal cord injury center: An introduction. Rehabilitation Psychology, 22(4), 165-178.

Dunst, C. J., Trivette, C. M., Gordon, N. J., Pletcher, L. L. (1989). Building and mobilizing informal family support networks. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Dush, D. M., Hirt, M. L., & Schroeder, H. E. (1989). Self-statement modification in the treatment of child behavior disorders: A meta-analysis. Psychological Bulletin, 106(1), 97-106.

Edgerton, R. B. (1967). The cloak of competence: Stigma in the lives of the mentally retarded. Berkeley: University of California Press.

Edwards, J. P. (1982). We are people first: Our handicaps are secondary. Portland, OR: Ednick.

Engelmann, S., & Carnine, D. (1982). Theory of instruction: Principles and applications. New York: Irvington Publishers, Inc.

Englert, C. S. (1983). Measuring special education teacher effectiveness. Exceptional Children, 50, 247-254.

Englert, C. S. (1984). Examining effective direct instruction practices in special education settings. Remedial and Special Education, 5, 38-47.

Espinosa, L., & Shearer, M. (1986). Family support in public school programs. In R. R. Fewell & P. F. Vadasy (Eds.). Families of handicapped children: Needs and supports across the life span, (pp. 253-277). Austin, TX: Pro-Ed.

Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. JASH, 13(3), 177-187.

Fewell, R. R., & Vadasy, P. F. (Eds.). (1986). Families of handicapped children: Needs and support across the life span. Austin, TX: Pro-Ed.

Fichten, C. S. (1988). Students with physical disabilities in higher education: Attitudes and beliefs that affect integration. In H. E. Yuker (Ed.), Attitudes towards persons with disabilities, (pp. 171-186), New York: Springer.

Fichten, C. S., & Amsel, R. (1986). Trait attributions about college students with a physical disability: Cirumplex analyses and methodological issues. Journal of Applied Social Psychology, 16(5), 410-427.

Fichten, C. S., Amsel, R., Bourdon, C. V., & Creti, L. (1987). Interaction between college students with physical disabilities and their professors. Journal of Applied Rehabilitation Counseling, 19(1), 13-20.

Fichten, C. S., Compton, V., & Amsel, R. (1985). Imagined empathy and attributions concerning activity preferences of physically disabled college students, 30(4), 235-239.

Fielder, C. M. (1988). Perceived psychosocial barriers related to physical disability: An investigation of alienation, internal processes and the application of practical skills. Dissertation Abstracts International, 49(6).

Fredericks, B. (1988). Tim becomes an Eagle Scout. Transition Summary, 5.

Garfield, S. L. (1986). Handbook of psychotherapy and behavior change. New York: Wiley.

Garmezy, N., & Rutter, M. (Eds.). (1988). Stress, coping, and development in children. Baltimore: Johns Hopkins.

Gardner, N. S. (1986). Sexuality. In J. A. Summers (Ed.), The Right to Grow Up: An Introduction to Adults with Developmental Disabilities, (pp. 45-66). Baltimore, MD: Paul H. Brookes.

Garfield, S. L., & Bergin, A. E. (1971). Handbook of psychotherapy and behavior change. (Third edition). New York: John Wiley & Sons.

Garner, J. B., & Campbell, P. H. (1987). Technology for persons with severe disabilities: Practical and ethical considerations. The Journal of Special Education, 21(3), 122-132.

Garris, P., & Hazinski. (1988). The effect of social skills training procedures on the acquisition of appropriate interpersonal skills for mentally retarded adults. Journal of Psychopathology and Behavioral Assessment, 10(3), 225-240.

Gaylord-Ross, R. (1989). Integration strategies for students with handicaps. Baltimore: Paul H. Brookes.

Gaylord-Ross, R. J., Haring, T. G., Breen, C., & Pitts-Conway, V. (1984). The training and generalization of social interaction skills with autistic youth. Journal of Applied Behavior Analysis, 17(2), 229-247.

Gertz, C. (1973). The interpretation of cultures. New York: Basic Books.

Glueckauf, R. L., Horley, J., Poushinsky, M. F., & Vogel, R. (1984). Assertiveness training for disabled individuals in wheelchairs: Preliminary findings. International Journal of Rehabilitation Research, 7, 441-443.

Goetz, L., Anderson, J., & Laten, S. (1989). Facilitation of family support through public school programs. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Goffman, I. (1973). The presentation of self in everyday life. New York: Overlook Press.

Goldenson, R. M., Dunham, J. R., & Dunham, C. S. (Eds.). (1978). Disability and rehabilitation handbook. New York: McGraw-Hill.

Goldfried, M.R., & D'Zurilla, T.J. (1969). A Behavior-analytic model for assessing competence. In C. D. Spielberger (Ed.), Current topics in clinical and community psychology, 1, 151-192. New York: Academic Press.

Gorenflo, C. W. (1986). The effect of information and agumentative communication technique on attitudes toward non-speaking individuals. Dissertation Abstracts International, 47(12).

Gottlieb, B. H. (Ed.). (1981). Social networks and social support. Beverly Hills: Sage.

Gottlieb, J., Semmel, M. I., Veldman, D. J. (1978). Correlates of social status among mainstreamed mentally retarded children. Journal of Educational Psychology, 70(3), 396-405.

Graham, S. & Harris, K.R. Components analysis of cognitive strategy instruction: Effects on learning disabled students' compositions and self-efficacy. (1989). Journal of Educational Psychology. 81(3), 353 - 361.

Granat, J. P. (1978). Assertiveness training and the mentally retarded. Rehabilitation Counseling Bulletin, 22, 100-107.

Gresham, F. M., & Elliott, S. N. (1987). The relationship between adaptive behavior and social skills: Issues in definition and assessment. The Journal of Special Education, 21(1), 167-181.

Grimes, J. W. (1989). The effects of assertion training on severely disabled students/clients. The Journal of Applied Rehabilitation Counseling, 11, 36-39.

Guess, D., & Siegel-Causey, E. (1985). Behavioral control and education of severely handicapped students: Who's doing what to whom? and why" In D. Bricker & J. Filler (Eds.). Severe mental retardation: From theory to practice, (pp. 230-244). Lancaster, PA: Division on Mental Retardation of the Council for Exceptional Children.

Guba, E., & Lincoln Y. (19890. Fourth Generation Evaluation. Newbury Park, CA: Sage Publications.

Halligan, F. G. (1983). Reactive depression and chronic illness: Counseling patients and their families. Personnel and Guidance Journal, 61(7), 401-406.

Halpern, A. S. (1985). Transition: A look at the foundations. Exceptional Children, 51(6), 479-486.

Halpern, A. S., Close, D. W., & Nelson, D. J. (1986). On my own. Baltimore, MD: Paul H. Brookes.

Halvorsen, A. T., Doering, K., Farron-Davis, F., Usilton, R., & Sailor, W. (1989). The role of parents and family members in planning severely disabled student's transitions from school. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptations to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Hampson, S. E., Glasgow, R. E., & Toobert, D. J. (in press). Personal models of diabetes and their relation to self-care activities. Health Psychology.

Hardy, J. D., & Smith, Ta. W. (1988). Cynical hostility and vulnerability to disease: Social support, life stress, and physiological response to conflict. Health Psychology, 7(5), 447-459.

Haring, T. G., Breen, C., Pitts-Conway, V., Lee, M., & Gaylord-Ross R. (1987). Adolescent peer tutoring and special friend experiences. Journal of the association for persons with severe handicaps, 12(4), 280-286.

Harter, S. (1981). A model of mastery motivation in children: Individual differences and developmental change. In S. Collins (Ed.). Minnesota symposium on child psychology, (Vol. 4). Hillsdale, NJ: Lawrence Erlbaum.

Harter, S. (1988). Manual for the self-perception profile for adolescents. Denver, CO: University of Denver.

Hawkins, N. E., & Singer, G. H. S. (1989). A skills training approach for assisting parents to cope with stress. In G. H. S. Singer, & L. Irvin (Eds.). Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Heimberg, R. C., Montgomery, D., Madsen, C. H., & Heimberg, J. S. (1977). Assertion training: A review of the literature. Behavior Therapy, 8, 953-971.

Henderson, R. W., Bergan, J. R., & Hunt, M. (1972). Development and validation of the Henderson Environmental Learning Process Scale. Journal of Social Psychology, 88, 185-196.

Heppner, P. P., & Petersen, C. H. (1982). The development and implications of a personal problem-solving inventory. Journal of Counseling Psychology, 29, 66-75.

Herzberger, S. D., Chan, E., & Katz, J. (1984). The development of an assertiveness self-report inventory. Journal of Personality Assessment, 48, 317-323.

Heward, W. L., Heron, T.E., Hill, D.S., & Trap-Porter, J. (Eds.). (1981). Focus on behavior analysis in education. Columbus, OH: Charles E. Merrill.

Hobbs, N., Perrin, J.M., & Ireys, H.T. (1985). Chronically ill children and their families. San Francisco, CA: Jossey-Bass.

Hoelter, J. W. (1985). The structure of self-conception: Conceptualization and measurement. Journal of Personality and Social Psychology, 49, 1392-1407.

Hohmann, G. W. (1975). Psychological aspects of treatment and rehabilitation of the spinal cord injured person. Clinical Orthopaedics, 112, 81-88.

Holloway, E.L. (1982). Interactional structure of the supervision interview. Journal of Counseling Psychology, 29, 309-317.

Holvoet, J., Guess, D., Mulligan, M., & Brown, F. (1980). The individualized curriculum sequencing model (II): A teaching strategy for severly handicapped students. Journal of the Association for the Severely Handicapped, 5(4), 337-351.

Horner, R. H., Meyer, L. H., & Fredericks, H. D. B. (Eds). (1986). Education of learners with severe handicaps: Exemplary service strategies. Baltimore, MD: Paul H. Brookes Publishing.

Hoskin, R., & Hostler, S. L. (1986). Learning experiences for physically disabled and chronically ill adolescents. Charlottesville, VA: University of Virginia.

Houghton, J., Bronicki, G. J., & Guess, D. (1987). Opportunities to express preferences and make choices among students with severe disabilities in classroom settings. JASH, 12(1), 18-27.

Hoy, C. (1986). Preventing learned helplessness. Academic Therapy, 22(1), 11-18.

Hughes, C. & Rusch, F. R. (1989). Teaching supported employees with severe mental retardation to solve problems. Journal of Applied Behavior Analysis, 22(4), 365-372.

Johnson, D. W., & Johnson, F. P. (1982). Joining together: Group theory and group skills (2nd ed.). Englewood Cliffs, NJ: Prentice-Hall.

Joyce, B.R., Showers, B. (1981). Teaching training research: Working hypotheses for program design and directions for further study. A paper presented to the Annual Meeting of the American Educational Research Association. Los Angeles, CA.

Lewis, C.E., Rachelefsky, G., Lewis, M.A., de la Sota, A., & Kaplan, M. A randomized trial of A.C.T. (asthma care training) for kids. (1984). Pediatrics, 74 (4), 478 - 485.

The ICD survey III: A report card on special education. (1989). Conducted for ICD-International Center for the Disabled. New York: Louis Harris and Associates, Inc.

The ICD survey of disabled Americans: Bringing disabled Americans into the mainstream. (1986). Conducted for ICD-International Center for the Disabled in cooperation with the National Council on the Handicapped. New York: Louis Harris and Associates, Inc.

Inman, D. P. (1979). Gaining control over tension in spastic muscles. In G. Hammerlynch (Ed.). Behavioral systems for the developmentally disabled: II. Institutional, clinic and community environments. New York: Brunner-Hazel.

Intagliata, J., & Doyle, N. (1984). Enhancing social support for parents of developmentally disabled children: Training in interpersonal problem solving skills. Mental Retardation, 221(1), 4-11.

Irvin, L. K. (1989). Evaluating family support programs. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Jakubowski, P., & Lange, A. J. (1978). The assertive option: Your rights & responsibilities. Champaign, IL: Research Press.

Jellison, J. A., Brooks, B. H., Huck, A. M. (1984). Structuring small groups and music reinforcement to facilitate positive interactions and acceptance of severely handicapped students in the regular music classroom. JRME, 12(4), 243-263.

Johnson, B. W., Redfield, D. L., Miller, R. L., & Simpson, R. E. (1983). The Coopersmith Self-Esteem Inventory: A construct validation study. Educational and Psychological Measurement, 43, 907-913.

Johnson, R., Johnson, D. W., DeWeerdt, N., Lyons, V., & Zaidman, B. (1983). Integrating severely adaptively handicapped seventh-grade students into constructive relationships with nonhandicapped peers in science class. American Journal of Mental Deficiency, 87(6), 611-618.

Johnson, R., Rynders, J., Johnson, D. W., Schmidt, B., & Haider, S. (1979). Interaction between handicapped and nonhandicapped teenagers as a function of situational goal structuring: Implications for mainstreaming. American Educational Research Journal, 16(2), 161-167.

Jones, M. L., & Ulicny, G. R. (1986). The independent living perspective: Applications to services for adults with developmental disabilities. In J. A. Summers (Ed.), The Right to Grow Up: An Introduction to Adults with Developmental Disabilities, (pp. 227-244). Baltimore, MD: Paul H. Brookes.

Kaplan, S.H., Greenfield, S. and Ware, J.E. Assessing the effects of physician-patient interactions on outcomes of chronic disease (1989). Medical Care, 27 (3), pp. S110 - S126.

Kazdin, A. E. (1974). Self-monitoring and behavior change. In M. J. Mahoney & C. E. Thoresen (Ed.), Self-Control: Power to the Person, (pp. 218-246). Belmont, CA: Wadsworth.

Keiter, J. (1979). Characteristics of the AADD population. Presented at the annual meeting of the American Academy on Mental Retardation.

Kessler, J. W. (1977). Parenting the handicapped child. Pediatric Annals, 1977, 6, 654-661.

Kirkham, M. A., Schilling, R. F., Norelius, K., & Schinke, S. P. (1986). Child: Care, Health and Development, 12, 313-323.

Kleinhammer-Tramill, P. J., Tramill, J. L., Schrepel, S. N., & Davis, S. F. (1983). Learned helplessness in learning disabled adolescents as a function of noncontingent rewards. Learning Disability Quarterly, 6, 61-66.

Kleinman, A. (1980). Patients and healers in the context of culture. Berkeley: University of California Press.

Kleinman, A. (1986). Social origins of distress and disease: Depression, neurasthenia, and pain in modern China. New Haven, CT: Yale University Press.

Kneedler, R. D., Hallahan, D. P., & Kauffman, J. M. (1984). Special education for today. NJ: Prentice Hall.

Kohr, M. A., Parrish, J. M., Neef, N. A., Driessen, J. R., & Hallinan, P. C. (1988, Spring). Communication skills training for parents: Experimental and social validation. Journal of Applied Behavior Analysis, 21, 21-30.

Kornblatt, E. S., & Heinrich, J. (1985). Needs and coping abilities in families of children with developmental disabilities. Mental Retardation, 23(1), 13-19.

Kozlowski, R. (1983). Promoting quality community living through formal support services and informal supports. (Report No. EC 171 138). Columbus, OH: Ohio State University, Ohio State Dept. of Mental Health and Mental Retardation, Columbus Div. of Mental Retardation and Developmental Disabilities. (ERIC Document Reproduction Service No. ED 250 900).

Kulkarni, M. R. (1985). Coping with disability inventory: A study of the reliability and validity of an instrument designed to measure coping behavior of physically disabled persons in the United States and India. Dissertation Information Service (UMI). Ann Arbor, MI: University Microfilms International.

Lasky, R. (1977). Structured existential therapy: A group approach to rehabilitation. In Marinelli and D. Orto (Eds.). The psychological and social impact of physical disability. New York: Springer.

Lavelle, N., & Keogh, B. (1980). Expectations and attributions of parents of handicapped children. New Directions for Exceptional Children, 4, 1-26.

Lazarus, R. S., & Folkman, S. (1984). Stress, Appraisal, and Coping. New York: Springer Publishing Company.

Leventhal, H., & Nerenz, D. (1985) The assessment of illness cognition. In P. Karoly (Ed.), Measurement strategies in health (pp. 517-554). New York: Wiley & Sons.

Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), Handbook of Psychology and Health (pp. 219-252). Hillsdale, NJ: Erlbaum.

Lewinsohn, P. M., Munoz, R. F., Youngren, M. A., & Zeiss, A. M. (1986). Control your depression: Reducing depression through learning self-control techniques, relaxation training, pleasant activities, social skills, constructed thinking, planning ahead, and more. New York: Prentice Hall.

Lewis, C.C., Pantell, R.H., & Sharp, L. (1991). Increasing patient knowledge, satisfaction, and involvement: randomized trial of a communication intervention. Pediatrics. 88 (2).

Lindemann, J. E.. (1981). Cerebral palsy. In J. E. Lindemann (Ed.), Psychological and behavioral aspects of physical disability, (pp.117-145). New York: Plenum Press.

Linville, P. W. (1982). Affective consequences of complexity regarding the self and others. In M. S. Clark & S. T. Fiske (Eds.), Affect and cognition (pp. 79-109). Hillsdale, NJ: Erlbaum.

Livneh, H. (1985) A unified approach to existing models of adaptation to disability: Part I - a model adaptation. Journal of Applied Rehabilitation Counseling, 17(1), 5-16.

Livneh, H. (1986). A unified approach to existing models of adaptation to disability: Part II - intervention strategies. Journal of Applied Rehabilitation Counseling, 17(2), 6-10.

Longone, J., & Burton, T. A. (1987). Teaching adaptive behavior skills to moderately and severely handicapped individuals: Best practices for facilitating independent living. The Journal of Special Education, 21(1), 149-165.

Lovett, H. (1985). Cognitive counseling and persons with special needs: Adapting behavioral approaches to the social context. New York: Praeger.

Luchow, J. P., Crowl, T. K., & Kahn, J. P. (1985). Learned helplessness: Perceived effect of ability and effort on academic performance among EH and LD/EH children. Journal of Learning Disabilities, 18(8), 470-474.

Mahoney, M. J., & Thoresen, C. E. (Eds.). (1974). Self-control: Power to the person. Belmont, CA: Wadsworth.

Makas, E. (1988). Positive attitudes toward disabled people: Disabled and nondisabled persons' perspectives. Journal of Social Issues, 44(1), 49-61.

Manus, G. I., & Manus, M. L. (1983). Psychosocial needs. In Programming adolescents with cerebral palsy and related disabilities, pp. 34-35. New York: United Cerebral Palsy Association, Inc. and Cathleen Lyle Murray Foundation.

Marchetti, A. G., Cecil, C. E., Graves, J., & Marchetti, D. C. (1984, June). Public transportation instruction: Comparison of classroom instruction, community instruction, and facility-grounds instruction. Mental Retardation, 22(3), 128-136.

Marcus, H. (1977). Self-schemata and processing information about the self. Journal of Personality and Social Psychology, 35, 63-78.

Marcus, H., & Wurf, E. (1987). The dynamic self-concept: A social psychological perspective. In M. R. Rosenzweig & L. W. Porter (Eds.), Annual Review of Psychology, Vol. 38 (pp. 299-377). Palo Alto, CA: Annual Reviews.

Margalit, M., & Shulman, S. (1986). Autonomy perceptions and anxiety expressions of learning disabled adolescents. Journal of Learning Disabilities, 19(5), 291-293.

Markel, G., & Greenbaum, J. (1981, August). Assertiveness training for parents of disabled children. The Exceptional Parent, pp. 17-22.

Marsh, H. W., Barnes, J., & Hocevar, D. (1985). Self-other agreement on multidimensional self-concept ratings: Factor analysis and multitrait-multimethod analysis. Journal of Personality and Social Psychology, 49, 1360-77.

Martin, J. E. (1989). Providing training in community and domestic skills. In L. W. Heal, J. I. Haney & A. R. Novakamodo (Eds.), Integration of developmental disabled individuals into the community. Baltimore, MD: Paul H. Brookes Publishing Co.

Matson, J. L., Manikam, R., Coe, D., Raymond, K., Taras, M., & Long. (1988). Training social skills to severely mentally retarded multiply handicapped adolescents. Research in Developmental Disabilities, 9, 195-208.

McCarthy, H. (1986). Making it in able-bodied America: Career development in young adults with physical disabilities. Journal of Applied Rehabilitation Counseling, 17(4), 30-38.

McGill J. (1978). We are people first - A book on self-advocacy. Lincoln, NE: Nebraska Advocacy Services.

Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: The example of hypertension. Health Psychology, 4, 115-135.

Meyer, L. H., & Putnam, J. (1988). Social Integration. In V. Van Haffelt, P. Strain, M. Hersen, (Eds.), Handbook of Developmental and Physical Disabilities (1st Edition), pp. 107-133. New York: Pergamon Press.

Mitchell, B. (1988). Who Chooses? Transition Summary, 5.

Moon, M. S., & Beale, A. V. (July, 1984). Vocational training and employment guidelines for parents. Transition Summary, 5-9. (Available from National Information Center for Children and Youth with Handicaps, Box 1492, Washington, D.C, 20013).

Morgan, B., & Leung, P. (1980). Effects of assertion training on acceptance of disability by physically disabled university students. Journal of Counseling Psychology, 27, 209-212.

Neistadt, M. E. (1986). Occupational therapy treatment goals for adults with developmental disabilities. The American Journal of Occupational Therapy, 40(10), 672-678.

New Hampshire Developmental Disabilities Council. (1990). Promises to keep. Concord, NH.

O'Brien, John. (1987). A guide to life-style planning: Using "The Activities Catalog" to integrate services and natural support systems. In B. Wilcox and G. T. Bellamy (Eds.), A comprehensive guide to the Activities Catalog: An alternative curriculum for youth and adults with severe disabilities. Baltimore, MD: Paul H. Brookes Publishing Co.

Odom, S., & Strain, P. (1986). A comparison of peer initiation and teacher-antecedent interventions for promoting reciprocal interactions of autistic preschoolers. Journal of Applied Behavior Analysis, 19, 59-71.

Page, R. C., Holland, B., Rand, M. E., Gartin, B. C., & Dowling, D. A. (1981,April/May/June). Assertiveness training groups with the disabled: A pilot study. Journal of Rehabilitation, pp. 52-55.

Patton, S. L. (February, 1985). The mentor project: Involving handicapped employees in the transition of handicapped youth from school to work. Final report. Waltham, MA: Russell and Associates, Inc. (ERIC Document Reproduction Service No. ED 280 249).

Paulson, P. R. (1984). A manual for maintaining support groups. Portland, OR: The Oregon Health Sciences University.

Peck, C. A. (1985). Increasing opportunities for social control by children with autism and severe handicaps: Effects on student behavior and perceived classroom climate. JASH, 10(4), 183-193.

Pennsylvania Evaluation Report. (1986). Prepared by the Conservation Company and The Human Organization Science Institute, Villanova University.

Perrin, E.C. & Shapiro, E. Health locus of control beliefs of healthy children, children with a chronic physical illness, and their mothers (1985). The Journal of Pediatrics. 627 - 633.

Peterson, C., & Stunkard, A. J. (1989). Personal control and health promotion. Social Science Medicine, 28(8), 819-828.

Pietruski, W., Everson, J., Goodwyn, R., & Wehman, P. (1985). Vocational training and curriculum for multihandicapped youth with cerebral palsy. Vocations in Technology. Richmond: Virginia Commonwealth University, School of Education.

Powers, L.E., & Sowers, J. (in press). Related service roles in promoting student independence and mastery. Journal of Occupational Therapy.

Powers, L.E., & Sowers, J. RISC: A student-directed model for independence and inclusion. Manuscript in preparation.

Reynolds, W. M., & Miller, K. L. (1983). Mastery Orientation Inventory. Madison, WI: Department of Educational Psychology, University of Wisconsin-Madison.

Reynolds, W. M., & Miller, K. L. (1984). Development and validation of a scale to measure learned helplessness. Paper presented at Annual Meeting of the American Educational Research Association, New Orleans, LA.

Reynolds, W. M. & Miller, K. L. (1985). Depression and learned helplessness in mentally retarded and nonmentally retarded adolescents: An initial investigation. Applied Research in Mental Retardation, 6, 295-306.

Rhoades, C. M., Browning, P. L., & Thorin, E. J. (1986). Self-help advocacy movement: A promising peer-support system for people with mental disabilities. Rehabilitation Literature, 47(1-2), 2-7.

Rhodes, L. and Ramsing, K. (1987). Economic evaluation of employment services: a review of applications. Journal of The Association for Persons with Severe Handicaps, 12(3), 175-181.

Robinson, N. M. & Robinson, H. B. (1976). The mentally retarded child (2nd ed.). New York: McGraw-Hill, Inc.

Rose, S. D., & Edleson, J. L. (1987). Working with children and adolescents in groups. San Francisco: Jossey-Bass.

Rosenberg, S., & Gara, M. A. (1985). The multiplicity of personal identity. In P. Shaver (Ed.), Review of personality and social psychology, Vol. 16 (pp. 87-113). Beverly Hills, CA: Sage.

Rosenshine, B. B. (1979). Content, time, and direct instruction. In P.L. Peterson and H. J. Walberg (Eds.), Research on teaching: Concepts, findings, and implications. Berkeley, CA: McCutchan.

Rousso, H. Mentoring empowers! How to start a networking project for disabled women and girls in your community (1988). The networking project for disabled women and girls, YWCA of the City of New York.

Rowitz, L. (1988, June). The forgotten ones: Adolescence and mental retardation. Mental Retardation, 115-117.

Rubin, D.H., Leventhal, J.M., Sadock, R.T., Letovsky, E., Schottland, P., Clemente, I., & McCarthy, P. Educational intervention by computer in childhood asthma: A randomized clinical trial testing the use of a new teaching intervention in childhood asthma. (1986). Pediatrics, 77 (1), 1 - 10.

Rule, W. R. (1984). Lifestyle counseling for adjustment to disability. Rockville, MD: Aspen.

Rusch, F. R. (1986). Competitive employment issues and strategies. Baltimore: Paul H. Brookes.

Rusch, F. R., & Mithaug, D. E. (1980). Vocational training for mentally retarded adults. Champaign, IL: Research Press.

Sailor, W., & Guess, D. (1983). Severely handicapped students: An instructional design. Boston: Houghton-Mifflin.

Sallis, J. F., Pinski, R. B., Grossman, R. M., Patterson, T. L., & Nader, P. R. (1988). The development of self-efficacy scales for health-related diet and exercise behaviors. Health Education Research, 3(3), 283-292.

Sailor, W., Gee, K., Goetz, L., & Graham, N. (1988). Progress in educating students with the most severe disabilities: Is there any? The Journal of the association of persons with severe handicaps, 13(2), 87-99.

Saxton, M. (1983). Peer counseling. In N. M. Crewe & K. Z. Irving (Eds.), Independent Living for Physically Disabled People, (pp. 171-186). San Francisco: Jossey-Bass.

Schinke, S. P., & Gilchrist, L. D. (1984). Life skills counseling with adolescents. Austin, TX: Pro-Ed.

Scherer, M. J. (1988). Assistive device utilization and quality-of-life in adults with spinal cord injuries or cerebral palsy. Journal of Applied Rehabilitation Counseling, 19(2), 21-30.

Schloss, P. J., Hughes, C. A., & Smith, M. A. (1988). Mental retardation: Community transition. Boston, MA: Little, Brown & Co.

Schloss, P. J., & Schloss, C. N. (1985). Contemporary issues in social skills research with mentally retarded persons. The Journal of Special Education, 19(3), 269-282.

Schunk, D.H. Self efficacy and cognitive achievement: Implications for students with learning problems. (1989). Journal of Learning Disabilities. 22 (1) 14-22.

Schutz, R. P. (1986). Establishing a parent-professional partnership to facilitate competitive employment. In F. R. Rusch (Ed.), Competitive Employment Issues and Strategies, (pp. 289-302). Baltimore, MD: Paul H. Brookes.

Scofield, M. E., Pape, D. A., McCracken, N., & Maki, D. R. (1980). An ecological model for promoting acceptance of disability. Journal of Applied Rehabilitation Counseling, 11(4), 183-187.

Searl, S.J. Jr. (1985). Thinking about the future: A manual for parents on transitions. Syracuse, New York: The Center on Human Policy, Syracuse, New York.

Seligman, M. E. P. (1975). Helplessness: On depression, development, and death. San Francisco: Freeman.

Sherer, M., Maddox, J. E., Mercandante, B., Prentice-Dunn, S., Jacobs, B., & Rogers, R. W. (1982). The self-efficacy scale: Construction and validation. Psychological Reports, 51, 663-671.

Sherman, R. G., Berling, B. S., & Oppenheimer, S. (1985). Increasing community independence for adolescents with spina bifida. Adolescence, 20(77), 1-13.

Sievert, A. L., Cuvo, A. J., & Davis, P. K. (1988, Fall). Journal of Applied Behavior Analysis, 21, 299-309.

Singer, G. H. S. (1988). Behavior Management Manual. Unpublished manuscript. Eugene, OR: Oregon Research Institute.

Singer, G. H. S., Irvine, B., & Irvin, L. K. (1989). Expanding the focus of behavioral parent training: A contextual approach. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Singer, G. H. S., and Irvin, L. K. (1988) Development of Positive Self-perceptions and Mastery Orientation in Children with Multiple Disabilities. Contract #H023T80013 between the U.S. Department of Education and the Oregon Research Institute.

Singer, G. H. S., & Irvin, L. K. (1989). Family caregiving, stress, and support. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Singer, G.H.S., & Irvin, L.K. (1984). Support and education for parents of deaf-blind children. Grant contract #G008630414 between the U.S. Department of Education and Oregon Research Institute.

Singer, G. S., Irvin, L. K., & Hawkins, N. (1988). Stress management training for parents of severely handicapped children. Mental Retardation, 26(5), 269-277.

Singer, G. S., Todis, B., & Powers, L. Qualitative investigations of correlates of self-esteem in children with physical disabilities. Manuscript in preparation.

Singh, N. N., Watson, J. E., & Winton, A. S. (1987). Parents' acceptability ratings of alternative treatments for use with mentally retarded children. Behavior Modification, 11(1), 17-26.

Slagle, D. (1982, May). Living independently with a personal care attendant. Paraplegia News, 24-28.

Slater, M. A., Martinez, M., & Habersang, R. (1989). Normalized family resources: A model for professionals serving families with a chronically ill or handicapped child. In G. H. S. Singer, & Irvin, L. K. (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul Brookes Publishing Co.

Smith, J.F., Fawcett, S.B., & Balcazar, F.E. (1991). Behaviour analysis of social-action constructs: The case of empowerment. Special Issue: Behavioural approaches to social and community issues. Behaviour Change. 8(1) 4 - 9.

Smith, N. (1981). Some thoughts on the care and keeping of attendants. Rehabilitation Gazette, 24, 53-55.

Snell, M. E. (Ed.). (1983). Systematic instruction of the moderately and severely handicapped, (2nd edition). Columbus, OH: Charles E. Merrill.

Snyder, M. (1984). When beliefs create reality. In L. Berkowitz (Ed.), Advances in experimental social psychology, Vol. 18 (pp. 247-305). New York: Academic Press.

Sowers, Jo-Ann. (1989). Supported employment: Critical parent roles. In G. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore: MD: Paul H. Brookes Publishing Co.

Sowers, Jo-Ann. (1983). Validation of the weekly activity interview (WAI): An instrument designed to measure the lifestyle of severely handicapped secondary-aged students. Unpublished doctoral dissertation, University of Oregon, Eugene.

Sowers, J., Jenkins, C., & Powers, L. (1988). Vocational education of persons with physical handicaps. In R. Gaylord-Ross (Ed.). Vocational education for persons with handicaps, (pp. 387-416).

Sowers, J., & Powers. L. (in press). Preparing students with cerebral palsy and mental retardation for the transition from school to community-based employment. Career Development for Exceptional Individuals.

Sowers, J. & Powers, L. (1988a). Training strategies for persons with physical and multiple disabilities. Eugene, OR: Oregon Research Institute.

Sowers, J. & Powers, L. (1988b). Task design alternatives for persons with physical and multiple disabilities. Eugene, OR: Oregon Research Institute.

Sowers, J., & Powers, L. (1989). Preparing students with cerebral palsy and mental retardation for the transition from school to community-based employment. Career Development for Exceptional Individuals, 12(1), 25-35.

Sowers, J., Rusch, F. R., Connis, R. T., & Cummings, L. E. (1980). Teaching mentally retarded adults to time-manage in a vocational setting. Journal of Applied Behavior Analysis, 13(1), 119-128.

Sowers, J., Singer, G., Irvin, L. K., & Inman, D. (1984). The Oregon Transition to Employment Project. Grant proposal. RFP 84.023 D: Handicapped Children's Model Demonstration Projects, Eugene, OR: Oregon Research Institute.

Starke, M. C. (1987). Enhancing social skills and self-perceptions of physically disabled young adults. Behavior Modification, 11(1), 3-16.

Steinhausen, H., Schindler, H., and Stephan, H. (1983). Correlates of psychopathology in sick children: An empirical model. Journal of the American Academy of Child Psychiatry, 22, 559 - 564.

Stelmach, M., Postman, J.,, Goldstein, S., & Shepard, K. (1981). Selected factors influencing job satisfaction of attendants of physically disabled adults. Rehabilitation Literature, 42, 130-137.

Stephens, R., & Haley, P. (1987, June). The empowerment dynamic: Planning and implementing a support group network. Portland, OR: Oregon Health Sciences University.

Stevens, J. (1986). Applied Multivariate Statistics for the Social Sciences. Hillsdale, NJ: Lawrence Erlbaum Associates.

Stillman, M. J. (1977). Women's health beliefs about cancer and breast self-examination. Nursing Research, 26, 121-127.

Stokes, T. F., & Baer, D. M. (1977). An implicit technology of generalization. Journal of Applied Behavior Analysis, 10, 349-367.

Stopford, V. (1987). Understanding disability: Causes, characteristics, and coping. London: Edward Arnold.

Strain, P., & Odom, S. (1986). Innovations in the education of preschool children with severe handicaps. In R. Horner, L. Meyer, & H. D. Frederick (Eds.). Education of learners with severe handicaps: Exemplary service strategies, (pp. 61-98). Baltimore, MD: Paul H. Brookes.

Stubbins, J. (Ed.) Social and psychological aspects of disability: A handbook for practitioners. Baltimore, MD: University Park Press.

Summers, J. A. (1986a). The right to grow up: An introduction to adults with developmental disabilities. Baltimore: Paul H. Brookes.

Summers, J. A. (1986b). Who are developmentally disabled adults? A closer look at the definition of developmental disabilities . In J. A. Summers (Ed.), The Right to Grow Up: An Introduction to Adults with Developmental Disabilities, (pp. 3-16). Baltimore, MD: Paul H. Brookes.

Summers, J. A., Behr, S. K., & Turnbull, A. P. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In G. H. S. Singer & L. K. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Swann, W. B. Jr. (1987). Identity negotiation: Where two roads meet. Journal of Personality and Social Psychology, 53, 1038-1051.

Taking charge of your life: A guide to independence for teens with physical disabilities. (1986). Washington, D.C.: Parent's Campaign for Handicapped Children and Youth. (Available from National Information Center for Children and Youth with Handicaps, Box 1492, Washington, D.C., 20036).

Taylor, S. E. (1990). Health psychology: The science and the field. American Psychologist, 45(1), 40-50.

Thomas, A., Bax, M., Coombes, K., Goldson, E., Smyth, D., & Whitmore, K. (1985). The health and social needs of physically handicapped young adults: Are they being met by the statutory services? Developmental Medicine & Child Neurology, 27(4)(Suppl. 50), 1-20.

Thorin, E., Browning, P., & Irvin, L. K. (September, 1986). Measuring knowledge of citizenship rights and responsibilities. Eugene, OR: University of Oregon.

Tisdelle, D. A., & St. Lawrence, J. S. (1988). Adolescent interpersonal problem-solving skills training: Social validation and generalization. Behavior Therapy, 19, 171-182.

Turk, D. C., Rudy, T. E., & Salovey, P. (1985). Implicit models of illness. Journal of Behavioral Medicine, 9, 453-474.

Turnbull, A. & Turnbull, R. J. (1985). Developing independence. Journal of Adolescent Health Care, 6(2), 108-119.

Turnbull, A. P., & Turnbull, H. R. (1986). Families, professionals and exceptionality: A special partnership. Columbus, OH: Merrill.

Turnbull, A. P., & Turnbull, H. R. (1989). Family perceptions research project. Lawrence, KA: University of Kansas.

Turnbull, H. R., Turnbull, A. P., Bronicki, G. J., Summers, J. A., & Roeder-Gordon, C. (1988). Disability and the family: A guide to decisions for adulthood. Baltimore, MD: Paul H. Brookes.

Turner, R. J., & Noh, S. (1988). Physical disability and depression: A longitudinal analysis. Journal of Health and Social Behavior, 20 (March), 23-27.

Ulicny, G.R., Adler, A.B., Kennedy, S.E. & Jones, M.L. (1987). A step-by-step guide to training and managing personal attendants, Volume 1: Consumer guide. Lawrence, Kansas: The Research and Training Center on Independent Living.

Ulicny, G. R., Adler, A. B., Jones, M. L. (1988, July-August-September). Consumer-directed attendant management. American Rehabilitation, pp. 22-31.

Ulicny, G. R., Elwell, J. S., & Jones, M. L. (1984). Disabled employers can increase their attendant management skills. Independent Living Forum, 2(3), Christine Boles, Michael Jones, Mark Mathews, & Susan Elkins (Eds.). Lawrence, Kansas: The Research and Training Center on Independent Living.

Ulicny, G., & Jones, M. L. (1985). Enhancing the attendant management skills of persons with disabilities. American Rehabilitation, 11(2), 18-20.

Ulicny, G. R., & Jones, M. L. (1987). Consumer management of attendant services. Rehabilitation Research Review. University of Kansas: Research and Training Center on Independent Living.

Varela, R. A. (1983). Changing social attitudes and legislation regarding disability. In N. Crewe & I. Zola (Eds.), Independent living for physically disabled people. San Francisco: Jossey-Bass Publishers.

Varela, R. A. (1986). Risks, rules, and resources: Self-advocacy and the parameters of decision making. In J. A. Summers (Ed.), The Right to Grow Up: An Introduction to Adults with Developmental Disabilities, (pp. 245-254). Baltimore, MD: Paul H. Brookes.

Varela, R. A. (1988). Self-determination and normalization among adolescents: The family as a crucible of values. Transition Summary, 5.

Vash, C. L. (1981). The psychology of disability. New York: Springer.

Voeltz, L. M. (1980). Children's attitudes toward handicapped peers. American Journal of Mental Deficiency, 84, 455-464.

Voeltz, L. M. (1982). Effects of structured interactions with severely handicapped peers on children's attitudes. American Journal of Mental Deficiency, 86, 380-390.

Voeltz, L., Hemphill, N. J., Brown, S. Kishi, G., Klein, R., Fruehling, R., Levy, G., Collie, J., & Kube, C. (1983). The special friends program: A trainer's manual for integrated school settings. (Report No. EC 172 529). Honolulu, HI: Hawaii University, Dept. of Special Education. (ERIC Document Reproduction Service No. ED 256 128).

Walker, B. (1989). Strategies for parent-teacher cooperation. In G. H. S. Singer, & Irvin, L. K. (Eds.), Support for caregiving families: Enabling positive adaptation to disability. Baltimore, MD: Paul H. Brookes Publishing Co.

Ward, M. J. (1988). The many facets of self-determination. Transition Summary, 5.

Warren, R. C. (1984). Reach for a difference - in the way you live: Guidelines for disabled adolescents. Rehabilitation Literature, 45(9-10), 274-281.

Wehman, P. (1981). Competitive employment: New horizons for severely disabled persons. Baltimore: MD: Paul H. Brookes.

Wehman, P., & Kregel, J. (1988). Adult employment programs. In R. Gaylord-Ross (Ed.). Vocational education for persons with handicaps, (pp. 205-233). Mountain View, CA: Mayfield Publishing Co.

Wehman, P., Moon, M. S., Everson, J. M., Wood, W., & Barcus, J. M. (1988). Transition from school to work: New challenges for youth with severe disabilities. Baltimore, MD: Paul H. Brookes.

Weiner, F. (1986). No apologies: A guide to living with a disability, written by the real authorities -- people with disabilities, their families and friends. New York: St. Martin's Press.

Wiggins, J. S. (1973). Personality and prediction: Principles of personality assessment. Reading, MA: Addison-Wesley.

Wilcox, B., & Bellamy, G. T. (1982). Design of high school programs for severely handicapped students. Baltimore, MD: Paul H. Brookes.

Wilcox, B., & Bellamy, G. T. (1987). A comprehensive guide to the activities catalog: An alternative curriculum for youth and adults with severe disabilities. Baltimore, MD: Paul H. Brookes.

Wilcox B. & Sailor, W. (1980). Service delivery issues: Integrated educational systems. In B. Wilcox & R. York (Eds.), Quality education for the severely handicapped: The federal investment. Washington, DC: U.S. Office of Special Education.

Williams, P., & Shoultz, B. (1984). We can speak for ourselves. Bloomington, IN: Indiana University Press.

Williams, R., & Long, J. (1979). Toward a self-managed life style. New York: Houghton-Mifflin.

Wolfensberger, W. (Ed.). (1972). The principle of normalization in human services. Downsview, Toronto, Canada: National Institute on Mental Retardation.

Workman, E. A. (1982). Teaching behavioral self-control to students. Austin, TX: Pro-Ed.

Wright, B. A. (1960). Physical disability - a psychological approach. New York: Harper & Row.

Wuerch, B. B., & Voeltz, L. M. (1982). Longitudinal leisure skills for severely handicapped learners: The Ho'onanea Curriculum Component. Baltimore, MD: Paul H. Brookes.

Zeaman, D., & House, B. J. (1960). Approach and avoidance in the discrimination learning of retardates. In D. Zeaman et al., (Eds.), Learning and transfer in mental defectives, Progress report No. 2, NIMH, USPHS, Research Grant M-1099 to University of Connecticut.

Zetlin, A. G., & Hosseini, A. (1989). Six postschool case studies of mildly learning handicapped young adults. Exceptional Children, 55(5), 405-411.

Zola, I.K. (1988, Sep-Oct). Aging and disability: Toward a unifying agenda. Special Issue: Aging and disabilities. Educational Gerontology. 14(5), 365-387.